INDIVIDUALS' PREFERENCES FOR DECISION-MAKING AND EXPERIENCES WITH TREATMENT BURDEN IN THE CONTEXT OF MULTIMORBIDITY AND DEMENTIA AMONG OLDER ADULTS IN THE UNITED STATES

by

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Abstract

Providing person-centered care is considered as the best practice of care for older adults with complex care needs, such as those with multimorbidity and dementia. Individuals' active engagement in health care is key to providing person-centered care. Individuals can engage in health care through shared decision-making with their providers. Outside of medical encounters, individuals can be more engaged through addressing treatment burden.

This thesis address literature gaps in individuals' role preferences for decision-making and experiences with treatment burden among older adults with multimorbidity and dementia, using recent data from a nationally representative survey. This thesis identifies multimorbidity patterns that are associated with decisional role preferences and experiences with treatment burden.

In Aim 1, we found that approximately 80% of older adults with multimoribidity stated that they prefer to leave decision up to providers (i.e., passive role). We found a graded association between a simple count of clusters and passive role preferences in decision-making (aOR=1.58, p=0.01 for two condition clusters; aOR=2.05, p<0.01 for three condition clusters; aOR=2.19, p<0.01 for four or more condition clusters).

In Aim 2, we found that approximately 75% of older adults with incident possible or probable dementia stated they prefer a passive role in decision-making. Having incident possible or probable dementia was

associated with higher odds of preferring a passive role relative to not having dementia after controlling for age, gender, educational attainment, and multimorbidity (aOR=1.64, p=0.02).

In Aim 3, we found that older adults with three or more condition clusters were statistically significantly more likely to experience any treatment burden than those with one condition cluster (45.1% vs. 34.8%, unadjusted OR=1.5, p<0.01). However, having three or more condition clusters was not associated with higher odds of treatment burden accounting for age, gender, martial status, educational attainment, depressive symptoms, and functional status.

These findings suggest the majority of older adults, even with multimorbidity or dementia, want to participate in decision-making. Using a simple count of condition clusters is a useful mean to explain variation in individuals' engagement in health care.

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Table of Contents

Chapter 1: Overall Aims

Overall Aims: Providing Person-centered Care to Older adults

Although the concept of patient-centered care was introduced several decades ago, [1] patient-centered care gained wider recognition after it was featured as one of the six aims for high-quality health care in the landmark Institute of Medicine (IOM) report *Crossing the Quality Chasm.*[2] According to the IOM report, patient-centered care is defined as "care that is respectful of and responsive to individual patient preferences, needs, and values". Patient-centered care is intrinsically a good thing from ethical perspective as it respects personal autonomy and fulfills providers' obligation to put patients' interest first. Moreover, patient-centered care is associated with better health outcomes, quality of life, [3,4], and personal well-being.[5].

Despite the term "patient-centered care" is widely used, there is a recent movement toward replacing it with the term "person-centered care". Person-centered care focuses on prevention and management of individuals' problem over time; whereas the notion of patient-centered care is predominantly visit-oriented that is temporary and limited to clinical encounters.[6] The term "person-centered care" also highlights the importance of knowing the person behind their illness and recognizing him/her as a human being with thoughts, feelings, and needs.[7] A

person-centered care approach to care is to use individuals' belief, values, and needs to set health goals and to guide care decisions.

A person-centered care approach has been advocated particularly in caring for people with multiple chronic conditions, i.e., multimorbidity and dementia,[8-11] on which standardized evidence-based care is less applicable.[12,13] Most randomized clinical trials and the evidence-based guidelines derived from them often not only exclude people with multimorbidity and dementia, but attempt to hold other contextual factors in social, environmental, and health care systems constant.[14-17] Following multiple fragmented and decontextualized evidence-based guideline at the same time may lead to significant treatment burden and potential harm to individuals.[13] Rather, care for people with multimorbidity and people with dementia should be person-centered, focusing on maximizing the health goals of individuals with unique sets of conditions, risks, values, and needs.

Knowing the person and his/her illness experiences, and engaging the person as an active participant in his or her own care are essential to provide person-centered care. Shared decision-making (SDM) is a promising approach for operationalizing person-centeredness. SDM is defined as the process of information exchange, joint consensus building, and agreement on the choice of treatment between individuals and providers.[18] During the process of SDM, individuals share their illness

experiences, beliefs, values and needs to providers, providers share information regarding the risk and benefit of treatment options, and providers and individuals set health goals and make treatment plans together given the specific combination of individuals' values, goals, risk and benefit associated with available treatment options.

In addition, assessing and addressing individuals' experiences with treatment burden may facilitate person-centered care delivery. Individuals' experiences with treatment burden may reflect their perspectives and preferences for treatment, it therefore should be incorporated in prioritizing possible treatment regimens.[9,19,20] Moreover, assessing treatment burden may increase individual activation, which refers to individuals' knowledge, skills, and confidences in managing his or her own health and care.[21] Individual activation is an important attribute to person-centered care.

Understanding individuals' preferences for decision-making and their experiences with treatment burden are important steps moving toward providing person-centered care. Person-centered care is considered as the best practice of care for people with multimorbidity and people with dementia. However, little is known about preferences for decision-making and their experiences with treatment burden for older adults with different multimorbidity patterns. Also, few studies have examined individual preferences for shared decision-making among older

adults with dementia as they are often excluded from decision-making in clinical settings.[22] Results from this dissertation will (1) provide insights on role preferences for decision-making among older adults with multimorbidity and older adults with dementia, and (2) identify multimorbidity patterns that are associated with greater odds of passive role preferences for decision-making and experiences with treatment burden. The latter information can be used to identify target population for potential intervention to encourage shared decision-making or to alleviate treatment burden, thus facilitate person-centered care delivery.

Chapter 2: Role Preferences for Decision-making among Older Adults with Multimorbidity in the United States

Abstract

Importance: Older adults living with multimorbidity represent a large and growing segment of the elderly population in the United States (U.S.). Shared decision-making (SDM) is the epitome of person-centered care for the multimorbidity population. Little is known about role preferences in medical decision-making among older adults with different multimorbidity patterns.

Objectives: (1) To examine if the presence of multimorbidity is associated with higher odds of passive role preferences in medical decision-making, and (2) to identify multimorbidity patterns that are associated with higher odds of passive role preferences in medical decision-making.

Methods: A retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study. We clustered multimorbidity patterns by (1) cardiopulmonary, (2) sensory-motor, (3) depression-dementia, (4) arthritis-osteoporosis, (5) cancer.

Study sample: 2,017 older adults living in community or residential settings. The study sample represented approximately 33.0 million Medicare beneficiaries aged 65 and older.

Main outcome of interest: Older adults were considered to have passive role preferences for decision-making if they stated that they prefer to leave decisions up to doctors.

Results: Approximately one in every seven older adults living in community or residential settings stated that they prefer a passive role (14.9%). We found a graded association between a simple count of clusters and passive role preferences in decision-making (aOR=1.58, p=0.01 for two condition clusters; aOR=2.05, p<0.01 for three condition clusters; aOR=2.19, p<0.01 for four or more condition clusters). Having four or more conditions were associated with higher odds of preferring a passive role (aOR=2.61, p<0.01 for four conditions, aOR=2.21, p<0.01 for five conditions). The depression-dementia cluster was associated higher odds of preferring a passive role (aOR=1.91, p<0.01); so was having the cardiopulmonary cluster (aOR=1.66, p<0.04).

Conclusions: Individuals' active participation in making medical decisions is essential to ensure such goals aligned with individuals' needs and values. Our findings suggest that encouraging SDM seems promising as the majority of older adults living in community or residential settings state that they prefer to participate in medical decision-making. However, older adults with multiple clusters of related conditions are more likely to state that they prefer to leave decisions up to their providers compared to older adults without multimorbidity. The number of condition clusters is a useful way to understand variation in

individuals' role preferences in decision-making among older adults with multimorbidity in the U.S.

Background

Multimorbidity, defined as coexistence of two or more chronic conditions, is a critical focus to "improve health and health care of older adults" – an explicit goal in Healthy People 2020.[1-3] In 2000, as many as 65% of older adults living in the United States (U.S.) had multimorbidity.[2,4] Multimorbidity becomes increasingly more common with age,[5] so the prevalence of multimorbidity is expected to steadily grow as the U.S. population is aging.[6] Multimorbidity is associated with higher mortality,[7,8] reduced functional status,[9,10] poorer quality of life,[11-13] and increased use of health services.[14,15]

Providing person-centered care, which reflects an older adult's preferences and health outcomes goals, is thought to be at the core of the management of older adults with multimorbidity,[16-19] One particular issue in multimorbidity is variation in patterns of coexisting conditions and inter-relatedness among these conditions. Individuals' preferences for the most and least desired outcomes and treatment goals likely differ even when being diagnosed with the same pattern of conditions because treatment options will likely differ due to difference in illness severity, functional status, prognosis, and personal priorities.[17,20] It is very difficult to find one best course of action for every individual with multimorbidity.[16] Moreover, physicians often have insufficient information to make decisions for individuals with multimorbidity, likely due to fragmented care and limited evidence on a treatment's net benefit

or harm within the context of an individual's particular set of risks, coexisting conditions, and goals. Person-centered care for multimorbidity requires coordinated input from individuals and multidisciplinary health care providers to meet each individual's needs.[19]

Shared decision-making (SDM) is a promising approach for operationalizing person-centeredness, with the goal to improve the degree to which medical care aligns with individuals' preferences, values, and goals. SDM is defined as the process of information exchange, joint consensus building, and agreement on the choice of treatment between individuals and providers.[21] A small number of studies have found that SDM is associated with better health outcomes,[22] greater satisfaction,[22] and reduced health care costs.[23,24] Greater use of SDM has been encouraged in new health policies to improve quality of care, such as Sections 3506 and 3021 of the Affordable Care Act.[25,26] SDM is especially critical in health situations in which there is not one clearly superior choice or a right answer on treatment based on available evidence, such as often occurs for individuals with multimorbidity.[27] Sharing of realistic treatment goals for providers and individuals and encouraging active individual engagement through SDM may facilitate more effective care, which in turn may increase or maintain quality of life among older adults with multimorbidity.[18,28,29]

Despite the promising benefit of SDM in providing person-centered care to older adults with multimorbidity, older adults are generally

portrayed as preferring to delegate medical decision-making to their health care providers rather than to share decision-making with their providers in the existing literature.[30-33] Being older and less educated are associated with passive role preferences in decision-making across studies;[30,32,34,35] but little is known about role preferences in medical decision-making among older adults with different multimorbidity patterns. More specifically, the heterogeneity of multimorbidity patterns is often less recognized in SDM research as few studies looked at multimorbidity beyond a simple condition count.[31,34] Previous studies indicate that the more conditions a person has, the more likely he or she prefers a passive role in medical decision-making.[34] However, older adults with multimorbidity vary not only by the number of conditions that coexist, but also by the characteristics of coexisting conditions and interaction among conditions. This variation may lead to diversity in illness severity, functional status, and treatment options, which may result in differences in preferences for SDM. For instance, individuals with severe diabetes or severe heart disease are less likely to prefer an active role in decision-making than individuals with mild hypertension.[30] Individuals with severe illness or people with poorer health status are more likely to prefer a passive role.[33,36-38] Treatment options, which often vary among older adults with multimorbidity due to inter-relatedness of coexisting conditions,[17] are also associated with individuals' preferences

in decision-making-- for example, individuals are more likely to make decisions for initiating medication than for undergoing surgery.[33]

Study Aims

To address the gap in the existing literature on preferences for SDM among the multimorbidity population, this study aims at providing a comprehensive examination of the relationship between role preferences for decision-making and different multimorbidity patterns among older adults in the U.S. The objectives of this study are (1) to examine if the presence of multimorbidity is associated with higher odds of passive role preferences in medical decision-making, and (2) to identify multimorbidity patterns that are associated with higher odds of passive role preferences in medical decision-making among older adults living in the U.S. We examine the study aims using recent nationally representative data from the U.S.

Methods

Study design and data source

This was a retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study (NHATS) collected in 2011 and 2012. NHATS is a population-based longitudinal study on the late-life disability trends and trajectories of older adults living in the contiguous U.S. The weighted NHATS sample is nationally representative given that it was drawn from the Medicare enrollment file that represented 96% of persons living in the contiguous U.S. who are

age 65 and over. The first round of the NHATS survey was conducted in 2011. Older adults were re-interviewed annually to track their functional status and health conditions. A stratified three-stage sampling design was used with randomly selected Medicare beneficiaries sampled with selected ZIP codes that were nested within selected counties. The probabilities of selection at each of the three stages were designed to yield equal probability samples and targeted sample sizes by age group and race/ethnicity group. Age 85 and older and non-Hispanic Black groups were oversampled. Of the 12,411 Medicare beneficiaries sampled for the first wave of the NHATS, 7,609 completed the in-person interview in the first wave, and 6,056 completed the in-person interview in the first two waves.[39] In the second wave, one-third of the older adults were randomly selected for a supplemental module on preferences for health care decision-making.

Study sample

Older adults who responded to the first two waves of NHATS and completed the supplemental module for health care decision-making in the second wave were included in the initial study population (n=2,063). We excluded 22 older adults who moved to nursing homes between the first and second waves of NHATS since a large proportion of this population had missing information used for the NHATS dementia classification method (see below in Measures section). A small number of

older adults who had missing responses to the health care decision-making module were also excluded (n=24).

The final sample for this study included 2,017 older adults living in community or residential settings who completed the supplemental module for health care decision-making in the second wave. With sample weights, the study sample represented approximately 33.0 million Medicare beneficiaries aged 65 and older in the U.S.

Conceptual framework

We outlined a conceptual framework encompassing both known and putative factors associated with individuals' role preferences in medical decision-making (**Figure 1**). We reviewed the existing literature on individuals' stated preferences in making medical decisions to find direct known factors to role preferences. We also reviewed literature on multimorbidity, the key independent variable, to identify the relationship between multimorbidity and the known and putative factors that were associated with role preferences for decision-making. Confounding socio-demographic variables included age, gender, race/ethnicity, educational attainment, income, marital status and acculturation factors. We hypothesized that being male, older, Black, Hispanic, poorer, less educated, married, and not acculturated are associated with higher odds of passive role preferences in decision-making[30,30,32,35,40-45] and higher risk of multimorbidity.[46-52] We also hypothesized that functional status is a confounding variable in the relationship—limited functional status is

associated with higher odds of passive role preferences in decision-making and higher risk of multimorbidity.[10,53] Relationship with providers is hypothesized to be a confounding variable—having a regular source of care is associated with higher odds of passive role preferences;[33,37,38] and having a third person during medical visits is associated with lower odds of passive role preferences as it is a sign that family members are more involved in medical decision-making.[35,54]

Measures

Older adults were read a statement - "People today are faced with many decisions about their health care—for example whether to start or change a medicine. We want to know how you prefer to have doctors and family or close friends help with decisions. Thinking about your doctors, do you prefer to…". Response categories included: (a) make decisions without much advice, (b) get their advice and then make decisions, (c) make decisions together (subsequently referred to as "share decisions"), and (d) leave decisions up to them.[34] In this study, the role preferences for medical decision-making were categorized into three distinct roles according to the widely adapted typology proposed by Charles in 1997: (1) active role, in which individuals decide which treatment option would be most appropriate, whether with or without advice from providers; (2) collaborative role, in which individuals and providers make decisions together; and (3) passive role, in which individuals leave decisions up to providers.[21,55]

Multimorbidity was measured using a combination of information that included self-reported doctor diagnosis of nine common chronic diseases, self-reported sensory impairment, the 4-item patient health questionnaire (PHQ-4) for depression and anxiety, and the dementia classification using the NHATS method (see below).[56] In the first wave of the NHATS survey, older adults were asked if they had been diagnosed by medical doctors with the following diseases: heart attack, heart disease including angina or congestive heart failure, hypertension, arthritis including osteoarthritis and rheumatoid arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer. In the second wave of the survey, older adults were asked if they were newly diagnosed with the same set of diseases since the last interview. Older adults were considered to have a given disease if they reported being diagnosed in either the 1st or 2nd wave.

Older adults were considered to have vision impairment if they reported blindness or reported that they do not see well enough, even with glasses or contacts, to recognize someone across the street, to watch television across the room, or to read newspaper print. Older adults were considered to have hearing impairment if they reported deafness, or reported that they do not hear well enough, even with hearing aids, to use the telephone, to hear conversations on the radio, or to carry on a conversation in a quiet room.[57] Depression and anxiety were measured by the PHQ-4, including the two-item patient health questionnaire (PHQ-

2) and the two-item generalized anxiety disorder scale (GAD-2). Response sets used for assessing level of depression and anxiety were “nearly everyday” (3), “more than half the days” (2), “several days” (1), or “not at all” (0). Scores were summed across the four items and then a sum score of 6 or higher was considered to have depression and anxiety.[58]

We adopted the dementia classification developed by the NHATS team.[56] Older adults were classified as none, possible, and probable dementia using a combination of information that included self-reported doctor diagnosis of Alzheimer’s disease or dementia, a score on the AD8 Dementia Screening Interview by proxy respondents, and a cognition battery on older adults’ memory, orientation, and executive function.[56] Older adults who scored at or lower than 1.5 standard deviations below the mean score in a given domain in the cognition battery were considered as impaired in that domain. Older adults who reported a diagnosis of dementia either by self or by proxy, older adults whose proxy respondents reported a score of 2 or higher in the AD8 interview, and older adults with impairment in at least two domains in the cognition battery were considered to have probable dementia. Impairment in only one domain in the cognition battery was classified as possible dementia in NHATS. Older adults who were classified as possible dementia mostly likely have mild cognitive impairment due to Alzheimer’s disease.[56,59,60] The classification used in NHATS was validated against the diagnosis information in the Aging, Demographics, and Memory Study (ADAMS)

Wave E that was conducted in 2010. We used a broad definition of dementia - including both probable and possible- in this study because this definition has good sensitivity (85.7%) and reasonable specificity (61.6%) to a medical diagnosis of dementia.[56]

Multimorbidity was measured in several different ways to differentiate patterns of multimorbidity. First, a simple count of the thirteen conditions was used. However, this measure applied equal weight to each condition and provided relatively limited information on what combination of conditions is associated with preferences for decision-making. Secondly, we used condition combinations to measure multimorbidity. However, condition combinations became complex exponentially with increased number of conditions. In order to summarize broad patterns of multimorbidity in an interpretable way, we also used a simple count of clusters of related conditions to measure multimorbidity. We adapted a set of condition clusters from a previously published study with one additional cluster for cancer to categorize the thirteen conditions that NHATS collected.[61] The clusters were: (1) cardiopulmonary cluster, including stroke, heart disease, heart attack, diabetes, high blood pressure, and lung disease; (2) sensory-motor cluster, including vision or hearing problems; (3) depression-dementia cluster; (4) arthritis-osteoporosis; and (5) cancer. Adaptation of the method in this study was chosen over other studies in condition clustering because (1) this set of condition clusters was shown to have

better predictability on functional status and self-assessed physical health in three years compared to a simple count of coexisting conditions, (2) condition clusters were developed in a survey on which diagnosis information was self-reported, like NHATS, and (3) the broad range of conditions included in developing the condition clusters overlapped with the information in NHATS very well.

Socio-demographic variables included in the analyses were age in ten-year groups, gender, educational attainment, race and ethnicity, annual household income, marital status, and acculturation factors. Annual household income was constructed in quartiles by marital status using the imputed total income value provided on the NHATS public use file. NHATS imputed total incomes for 44% of individuals who did not provide a total income amount.[62] Cutoffs for quartiles were $10,503, $17,000, and $29,900 for unmarried older adults, and $25,000, $42,200, and $70,000 for married older adults, respectively. Acculturation factors were measured by self-reported English proficiency and length of residence in the U.S. Older adults who speak English only or who speak English very well or well were considered to have English proficiency, whereas older adults who speak English not well or not at all were considered to not have English proficiency- as suggested in other published studies.[63] Length of residence was classified into three categories, including born in the U.S., born in a foreign country and

moved to the U.S. before age 45, and born in a foreign country and moved to the U.S. at age 45 or older.

Self-reported needing help or difficulty with activities of daily living (ADLs) and instrumental activities of daily living (IADL) were used to measure functional status. Older adults were asked how often they perform ADLs, including self-care activities (eating, getting cleaned up, using toilet, and getting dressed) and mobility (getting inside, outside of house, and getting out of bed) without help in the last month.[64] They also were asked whether they had help doing IADLs, mostly household tasks including doing laundry, shopping, preparing hot meals, handling banking and bills, and tracking medications in the last month.[65] An older adult was considered to have limitation in self-care activities or mobility if he/she reported having problems performing at least one activity in self-care activities or mobility, respectively, without help of any person.[66] Household tasks limitation was identified if an older adult reported having difficulty doing at least one household task independently or having someone to do for or to do with for at least one household task because of health reasons.[67]

We used self-reported having a usual source of care and self-reported seeing the usual source of care in the last year to measure if there is a consistent relationship between an older adult and her/his usual source of care. In order to understand if the relationship with providers involved a third person, as it is quite common that a family

member presents during medical visits for older adults,[68] older adults were asked if there was a third person sitting in during doctor visits and it was considered as a sign that family is more involved in care.

Analyses

Descriptive analyses were conducted to explore differences in role preferences for decision-making, the dependent variable, by older adults' age, gender, educational attainment, race/ethnicity, annual household income, marital status, acculturation factors (language proficiency and length of residence), functional status, usual source of care (self-reported a usual source of care and saw the doctor in the last year), a third person during medical visits, and multimorbidity patterns.

In the preliminary analyses, we found that older adults who preferred an active role shared many similar characteristics with older adults who preferred a collaborative role. Due to the relative small sample size of the study and small difference between these two groups, we did not have enough statistical power to compare older adults with collaborative role preferences to older adults with active role preferences. In addition, this analysis built upon previous work by Wolff and Boyd (2015), which also categorized decision-making preferences to leaving decisions up to the doctor (i.e., passive) versus others.[34] Therefore, the regression analyses in the study focused on comparing people who preferred a passive role against others who preferred either an active or a collaborative role in decision-making.

We conducted simple regression models for bivariate analysis - which examined the strength and magnitude of socio-demographic characteristics, functional status, relationship with providers, and multimorbidity patterns of older adults in relation to passive role preferences. We also constructed multiple logistic regression models to determine whether preferences for a passive role in decision-making were associated with multimorbidity after adjusting for a set of confounding variables. The basic model for multiple logistic regression model was specified as: $Y = \beta_0 + \beta_1 X^{multimorbidity} + \beta_2 X^{confounding\ variables} + \epsilon$. Since multimorbidity, the key independent variable, was measured in several ways, four sets of parallel logistic regression models were fitted – one using the presence of multimorbidity (Model 1), one using a simple count of condition clusters in categories (Model 2), one using a simple count of conditions in categories (Model 3a & 3b), and one using the presence of the five condition clusters (Model 4). We did not include a multiple regression model using condition combinations to measure multimorbidity because of small sizes of each of the top five commonly occurring combinations. Using the backward elimination process with cut-off p-value of 0.05 as guidance, age, gender, educational attainment, English proficiency, and mobility limitation were included in the multiple regression models. The self-care activities limitation variable was selected from the backward elimination process but dropped from the multiple

regression models as it was consistently insignificant in model 2, 3a, 3b, and 4.

To better understand the relationship between different multimorbidity patterns and passive role preferences, we constructed multiple regression models for subgroups. Model 3a examined the relationship between the number of chronic conditions in categories (0, 1, 2, 3, 4, and 5 or more) and the preferences for a passive role. Given that the majority of people who had two or more conditions had conditions that fell into two or more clusters, we suspected that the association between having two or more conditions and role preferences might be largely explained by the association between having two or more clusters and role preferences (**Appendix Table 1**). Thus we constructed a model (Model 3b) which used the same structure as Model 3a but restricted to older adults whose conditions fall into one condition cluster (n=399).

As part of sensitivity analyses, we also included interaction terms for the presence of multimorbidity and a set of significant confounding variables in the main model, including age, gender, educational attainment, English proficiency, and mobility limitation given that some literature implied that disease status might be an effect modifier.[69-71] However, none of the interaction terms showed statistical significance, so we did not include interaction terms in the multiple regression models.

The analyses were conducted in Stata SE 11(StataCorp, College Station, TX). We used analytic weights to account for the complex sampling strategy and the svy commands in Stata to produce standard errors on the estimates. The subpop option in Stata was used to produce point and variance estimates for the study population that is a subset of total population of NHATS. A significance level of $\alpha = 0.05$ was used for analyses.

Results

The study population represented 33.0 million adults ages 65 or older and living in community or residential settings in the U.S. Over half of them were between 65 and 74 (54.4%), 33.4% were between 75 and 84, and 12.2% were older than age 85. Females accounted for 57.2% of the study population. The major race and ethnicity was White, non-Hispanic (81.1%), followed by Black, non-Hispanic (8.1%), Hispanic (6.1%), and others (4.7%) (**Table 1**).

Approximately one in every seven older adults living in community or residential settings stated that they prefer to leave decisions up to providers, i.e., a passive role, (14.9%, 4.9 million) with the remainder relatively evenly divided between preferring an active role (47.5%, 15.6 million), or a collaborative role (37.6%, 12.4 million). The odds of preferring a passive role over an active or a collaborative role varied widely by socio-demographic characteristics, functional status, and relationship with providers. With greater age, having high school diploma,

lower annual household income, being widowed, immigrating to U.S. later in life, and no English proficiency, older adults were more likely to prefer a passive role in medical decision-making. For example, older adults who did not have high school diploma had more than twice the odds of preferring a passive role relative to people who had high school diploma (OR=2.40, $p<0.01$). Older adults who did not have English proficiency had four times the odds of preferring a passive role than those who are proficient in English (OR=4.02, $p<0.01$). Older adults were more likely to prefer a passive role with limitation in self-care activities, mobility, or household tasks. Older adults who had a third person sit in medical visits were also more likely to prefer a passive role (OR=1.78, $p<0.01$) (**Table 1**).

The odds of preferring a passive role in decision-making among older adults varied by multimorbidity patterns (**Table 2**). Older adults who had two or more conditions (i.e., multimorbidity) had more than twice of the odds stating that they preferred a passive role over an active or a collaborative role (18.9%) compared to those had one condition or none (8.9%, OR=2.35, $p<0.01$). The proportion of older adults who preferred a passive role increased with greater number of conditions. Older adults who had three or more conditions were more likely to prefer a passive role in medical decision-making, relative to those had one condition (OR=1.77, $p=0.03$ for three conditions; OR=3.05, $p<0.01$ for four conditions; and OR=3.31, $p<0.01$ for five or more conditions,

respectively). Interestingly, older adults who had two conditions were not statistically significantly more likely to state that they preferred a passive role than older adults who had one condition (OR=1.27, p=0.44).

With respect to condition clusters, older adults who had two or more different condition clusters were more likely to state that they preferred a passive role than those who had one cluster (OR=2.13, p<0.01, **Table 2**). Also, there was a graded association between the number of condition clusters and passive role preferences - increased number of condition clusters was associated with higher odds of passive role preferences among older adults who had at least two condition clusters (OR=1.62, p<0.01 for two condition clusters; OR=2.50, p<0.01 for three condition clusters, OR=3.60, p<0.01 for four or more condition clusters). In terms of specific condition clusters, having the depression-dementia condition cluster was associated with 3-fold higher odds of preferring a passive role than those who did not (OR=2.98, p<0.01). The presence of cardiopulmonary, sensory-motor, and arthritis-osteoporosis condition cluster were also associated with higher odds of preferring a passive role. The combination of hypertension and cancer was statistically significantly associated with lower odds of passive role preferences among older adults (OR=0.22, p=0.03, **Table 2**); however, the frequency of the combination was small (**Appendix Table 1**).

Multiple regression models that examined the relationship of multimorbidity patterns and decision-making preferences of older adults

were consistent with the findings from simple regression models - indicating that some multimorbidity patterns were associated with higher odds of passive role preferences (**Table 3**). Having multimorbidity (OR=1.77, p<0.01) overall was associated with higher odds of passive role preferences compared to those with one or on chronic conditions after adjusting for age, gender, educational attainment, English proficiency, and mobility limitation (Model 1).

We found a graded association between the number of condition clusters and odds of passive role preferences - the more clusters of related conditions an older adult had, the higher odds he or she preferred a passive role (OR=1.58, p=0.01 for two condition clusters; OR=2.05, p<0.01 for three condition clusters; OR=2.19, p<0.01 for four or more condition clusters, Model 2); however, a graded association was not found between the number of conditions and passive role preferences. Having two or three conditions was not statistically significantly associated with higher odds of preferring a passive role compared to having zero or single condition (OR=1.31, p=0.37 for two conditions; OR=1.47, p=0.14 for three conditions), but having four more conditions were associated with higher odds of preferring a passive role (OR=2.61, p<0.01 for four conditions, OR=2.21, p<0.01 for five or more conditions, Model 3a). The association with passive role preferences was likely due to greater number of condition clusters that older adults with four or more conditions had, rather than the single count itself (**Appendix Table 2**).

This is supported by the finding that showed having multimorbidity was not associated with higher odds of passive role preferences when conditions all fell into the same cluster (OR=1.11, p=0.80, Model 3b). Being categorized as having conditions associated with the depression-dementia cluster was associated higher odds of preferring a passive role (OR=1.91, p<0.01); so was having the cardiopulmonary cluster (OR=1.66, p=0.04, Model 4)

Discussion

SDM is the epitome of person-centered care for the multimorbidity population.[27] Drawing upon data from a representative survey on the elderly population in U.S., we find that encouraging SDM seems promising as the majority of older adults living in community or residential settings state that they prefer to participate in medical decision-making. However, older adults are more likely to state that they prefer to leave decisions up to providers if they have multiple clusters of related conditions compared to older adults who have only one cluster of related conditions or none. The more clusters of related conditions an older adult has, the more likely he or she prefers a passive role in medical decision-making. We also find that older adults with four or more conditions, who mostly have multiple clusters of related conditions, have more than twice the odds of preferring a passive role compared to people with zero or one chronic condition. This study demonstrates that

the number of condition clusters is a useful way to understand variation in individuals' role preferences in decision-making among older adults with multimorbidity in the U.S.

Approximately 15% of older adults with multimorbidity in the U.S. state that they prefer a passive role in medical decision-making, which agrees well with a recent published study in an elderly population with three or more conditions in Sweden.[31] We find that the presence of multimorbidity is associated with higher odds of passive role preferences. Other published population-based studies in the U.S., which include both younger and older adults, have related findings-- suggesting that people who rate their own health as poor, which is linked to the presence of multimorbidity,[72] are more likely to prefer a passive role in decision-making.[33,37,38] Moreover, this study addresses the gap in the existing literature by highlighting some multimorbidity patterns that are associated with higher odds of passive role preferences, such as multiple condition clusters.

Managing chronic conditions involves a series of multiple decisions in relation to treatment choices, symptoms managements, and lifestyle changes that recur at varying frequencies throughout the course of the illness,[73] and individuals' desire to participate in medical decision-making depends on many individual and systematic characteristics. Individuals may prefer a passive role in decision-making if SDM is not well received by providers or if they experience barriers to participate

from previous experiences.[21,31] With an increased number of unrelated conditions, a provider is more likely to face competing demand in time to address other discordant conditions during a single visit, which may lead to communication barriers,[74] and less desired environment for SDM because SDM is a dynamic process that takes time. Caring for individuals with multimorbidity often involves multiple providers with different specialties and there is often limited care coordination across providers.[19] Conflicting advice and contradictory treatment regimens across several providers may discourage individuals from actively participating in decision-making as they may feel like they do not have sufficient information to make the right decisions.[75-77] Limited availability of evidence-based guidance and tools on multimorbidity management create barriers to information sharing – a prerequisite to SDM – as most often potential consequences of treatments are less understood when other conditions coexist.[78,79] Time pressure during visits, communication barriers, and information deficits are likely to lead to greater preferences for passive roles among individuals with multimorbidity.[21,31]

Complexity in self-management activities caused by multimorbidity may also prevent individuals from wanting to participate in medical decision-making. The amount of effort required for caring for multimorbidity is usually more than a simple aggregation of effort required for individual conditions, especially when coexisting conditions do not require related self-management activities and lifestyle

modifications.[20,73] Many disease management programs and decision aids are tailored toward a specific disease,[80] which provide limited support for individuals with multimorbidity to gain personal expertise and sufficient knowledge and skills regarding self-management activities and treatment choices. Lack of knowledge, skills, and confidence regarding complex self-management activities may contribute to greater passive role preferences among individuals with multiomorbidity.[73,76,81,82,102]

This study provides new insights showing that the patterns in which older adults' conditions frequently coexisted are associated with their preferences for a passive role in medical decision-making. Previous studies have found that individuals' preferences in decision-making role vary by disease trajectory and their illness experiences,[44,83-86] As mentioned above, the multimorbidity population shares vast clinical heterogeneity partly because of the variation in multimorbidity patterns. In research, multimorbidity patterns are often reduced to a simple count of conditions. Such approach provides a simple analytical tool, but addresses very limited variation in multimorbidity patterns. The number of conditions a person has may only explain some degree of variation in the complexity in care need for multimorbidity if condition characteristics and the inter-relatedness between conditions are not accounted for.

To better address the heterogeneity in multimorbidity populations in a practical way, this study examines the heterogeneity of

multimorbidity by condition clusters and condition combinations, and to our knowledge this is a novel approach in SDM literature. Although clustering of conditions does not necessarily indicate pathophysiological relations, such as shared risk factors, or the degree that multiple conditions interact and compound in treatment plans, it provides a practical approach to operationalize inter-relatedness between conditions, as well provides some basic information regarding common characteristics shared by the conditions in the same cluster.[87,88] Two conditions are grouped into the same condition cluster if the presence of one is significantly associated with the presence of another in statistics. We find that having two or more condition clusters, or, in other words, having two or more unrelated conditions, is associated with higher odds of passive role preferences. Even more interestingly, our analysis shows that the association between multimorbidity and passive role preferences may be largely explained by the strong association between having two or more condition clusters and passive role preferences given that the association between multimorbidity and passive role preferences is not present in a subgroup of older adults where multiple conditions fell into one cluster.

This study also finds that having the depression-dementia cluster is associated with higher odds of passive role preferences. This finding diverges from existing literature that shows depressed individuals want to more actively engage in medical decisions,[30,89] as do the majority of

individuals with a dementia diagnosis.[90-93] Nevertheless, some literature indicates that individuals with dementia are likely to be excluded from participation as dementia progresses.[93,94] Further examination on cognition status in relation to passive role preferences may provide additional insights on the observed association.

This study has a few limitations. First, multimorbidity was based on self-reported information on a number of disease diagnoses and conditions. There was very limited information on disease severity and length of diseases duration available in NHATS. The types of disease diagnoses and conditions were limited. Nevertheless, the diagnoses and conditions in NHATS covered a good number of diseases and conditions that are prevalent or have significant impact on disability in the elderly population. Research showed that self-reported diagnoses have generally good agreement in comparison with physician-reported diagnoses.[95] Secondly, the primary outcome of this study was older adults' role preferences for decision-making, but whether older adults actually participate in decision-making cannot be determined by this study. Nevertheless, better understanding of individuals' role preferences is critical. Previous literature suggested that discordance between preferred role and actual role may lead to Individual dissatisfaction.[96] Finally, this study used cross-sectional data, so causal inferences between role preferences for decision-making and multimorbidity patterns cannot be drawn.

Despite these limitations, this study is unique and has several distinct strengths. To our knowledge, this is the first study that examines role preferences for decision-making among older adults in the U.S. in relation to the presence and different patterns of multimorbidity. We examine multimorbidity in condition clusters in addition to a commonly used approach, a simple condition count, in order to better differentiate multimorbidity patterns. Very few studies in SDM have looked at multimorbidity or comorbidity beyond a simple condition count.[31,34] The use of a complex survey that is nationally representative of the U.S. elderly population is another strength. Information generated from NHATS has great external validity because NHATS uses Medicare enrollment files as the sampling frame. Using a nationally representative sample is an improvement from the existing SDM literature as it is mostly limited in generalizability due to small sample sizes, non-random sampling, and selected conditions.[30,32,44,69,97-100]

Implication for research and practices

Multimorbidity is a norm rather than an exception that older adults in the U.S. experience nowadays, and the importance of multimorbidity on health outcomes and quality of care has been well-recognized;[7-15] however, the way that multimorbidity has been operationalized in the large body of multimorbidity literature may not be sufficient to account for different levels of complexity involved in managing multimorbidity. To better serve the needs of the multimorbidity

population, finding a practical measure that is feasible to adopt without oversimplifying the diversity of the population is key in multimorbidity research. This analysis demonstrates that by measuring multimorbidity in multiple ways –using the generally accepted approach of a simple condition count and the condition cluster approach- we provide new insights that the degree of multimorbidity, as measured by number of coexisting clusters, is associated with older adults' role preferences in decision-making, which extends beyond the existing literature on multimorbidity and role preferences.

In addition, this study illuminates potential target groups among the multimorbidity population, i.e., those with multiple condition clusters, in which to encourage SDM. Although a stated preference for a passive role may reflect underlying personal traits for some individuals, it may also reflect individual previous medical encounters and illness experiences.[21] Future research is needed to identify potential barriers and facilitators to encourage individual involvement in decision-making among older adults with multiple clusters of related conditions, and such information can be incorporated into SDM programs to caring for multimorbidity; therefore potentially improving quality of care received among older adults with multimorbidity in the U.S.

Conclusion

Person-centered care for older adults with multimorbidity requires individuals and providers to set realistic treatment goals together. Individuals' active participation in making medical decisions is essential to ensure such goals aligned with individuals' needs and values. Despite a trend toward greater individuals' preferences for an active role in decision-making,[34,101] older adults with multiple clusters of related conditions are more likely to state that they prefer to leave decisions up to their providers compared to their counterparts with only one cluster of conditions. The number of condition clusters is a useful way to understand variation in individuals' role preferences in decision-making among older adults with multimorbidity in the U.S.

Table 1: Socio-demographics, functional status, and relationship with providers among older adults living in community/residential settings in the U.S.

	All	Preferred role in decision making			Passive vs. others	
		Active	Collaborative	Passive	OR	P-value
	(Column %)	(Row %)	(Row %)	(Row %)		
Total (in millions)	33.0	15.6	12.4	4.9		
		47.5%	37.6%	14.9%		
Age in categories						
Age 65-74	54.4%	47.3%	38.4%	13.8%	Ref	
Age 75-84	33.4%	48.0%	34.9%	17.3%	1.29	0.15
Age 85+	12.2%	39.7%	33.7%	28.2%	2.39	<0.01
Male	42.8%	43.1%	38.0%	19.2%	1.35	0.06
Female	57.2%	49.2%	35.7%	14.8%	Ref	
Race and ethnicity						
1 White, non-Hispanic	81.1%	46.9%	37.1%	16.0%	Ref	
2 Black, non-Hispanic	8.1%	44.3%	35.8%	20.2%	1.32	0.14
3 Hispanic	6.1%	52.0%	34.3%	13.7%	0.84	0.61
4 Others	4.7%	39.7%	34.3%	27.0%	1.92	0.09
Less than high school	21.3%	41.6%	31.9%	28.0%	2.40	<0.01
High school diploma	78.7%	48.0%	38.0%	13.7%	Ref	
Annual household income						
1 1st lowest quartile	20.1%	44.7%	33.8%	22.0%	2.16	<0.01
2 2nd quartile	23.1%	43.8%	37.0%	19.7%	1.89	0.01
3 3rd quartile	23.2%	50.4%	33.1%	16.9%	1.56	0.02
4 4th quartile	33.6%	47.2%	40.8%	11.4%	Ref	
Marital status						
1 Married/Living with a partner	57.4%	45.1%	40.4%	14.1%	Ref	
2 Widowed	25.9%	47.5%	32.4%	20.5%	1.56	0.01
3 Separated/Divorced / Never married	16.7%	50.5%	30.5%	19.7%	1.48	0.05

	All	Preferred role in decision making			Passive vs. others	
		Active	Collaborative	Passive	OR	P-value
	(Column %)	(Row %)	(Row %)	(Row %)		
Length of stay in U.S.						
1 U.S. born	89.5%	46.6%	36.9%	16.4%	Ref	
2 Foreign born and move to U.S. before age 45	8.4%	49.4%	35.8%	14.7%	0.88	0.65
3 Foreign born and move to U.S. at or after age 45	2.1%	35.5%	31.4%	35.8%	2.70	0.04
English proficiency	97.8%	46.7%	37.1%	16.1%	Ref	
Not have English proficiency	2.2%	42.4%	13.6%	44.0%	4.02	0.01
Self-care limitation	24.3%	40.5%	34.4%	26.4%	2.23	<0.01
No self-care limitation	75.7%	48.6%	37.4%	13.6%	Ref	
Mobility limitation	29.2%	41.0%	33.5%	26.8%	2.48	<0.01
No mobility limitation	70.8%	48.9%	38.0%	12.6%	Ref	
Household tasks limitation	34.3%	40.6%	35.5%	24.8%	2.27	<0.01
No household tasks limitation	65.7%	49.7%	37.3%	12.5%	Ref	
Have usual source of care (USC)	95.7%	45.5%	37.6%	16.9%	1.52	0.25
Do not have USC	4.3%	71.5%	17.1%	12.0%	Ref	
Saw USC last year	93.5%	45.9%	37.3%	16.8%	1.15	0.70
Not see USC last year	6.5%	56.6%	28.2%	14.9%	Ref	
Third person sit in visits	35.4%	39.2%	39.3%	22.2%	1.78	<0.01
No third person sit in visits	64.6%	50.6%	35.3%	13.7%	Ref	

Unweighted n=2,017

Table 2: Role preferences in decision-making by multimorbidity patterns among older lived in community/residential settings in U.S.

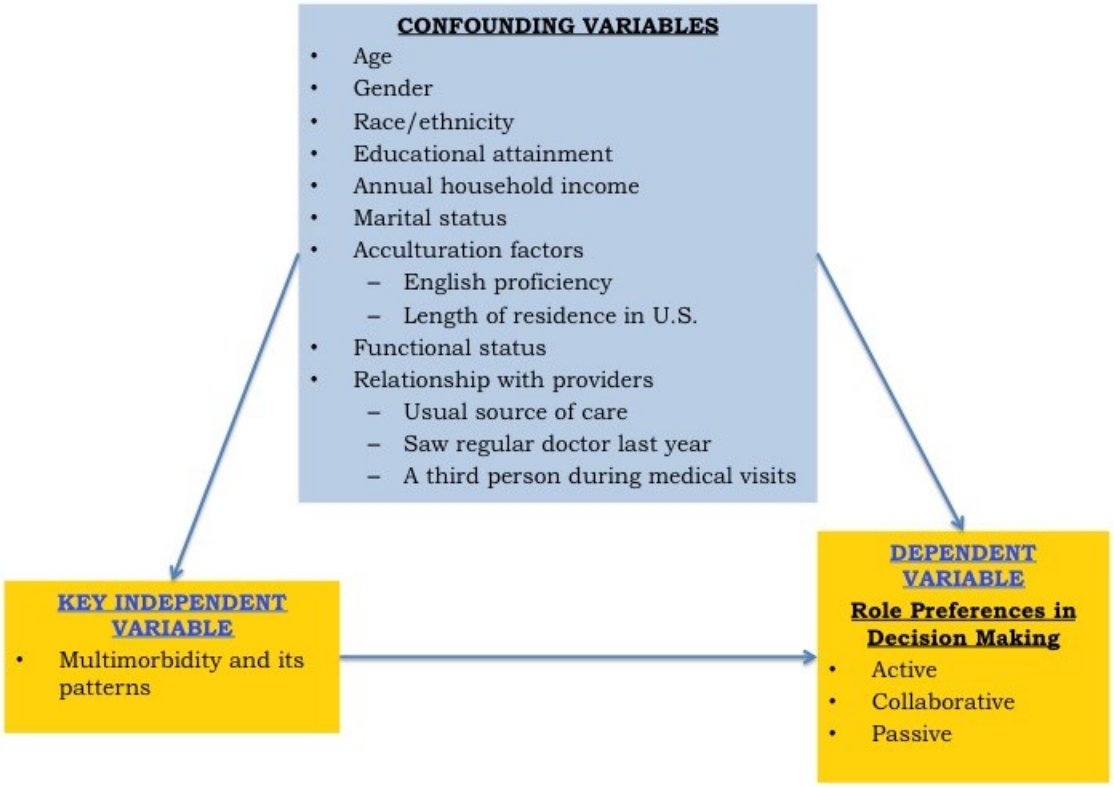
	Preferred role in decision making			Passive vs others	
Row %	Active	Collaborative	Passive	OR	p-value
	15.6	12.4	4.9		
All	47.5%	37.6%	14.9'%		
No multimorbidity	56.3%	33.8%	8.9%	Ref	
Multimorbidity	44.0%	37.5%	18.9%	2.35	<0.01
Number of conditions in categories					
0 no condition	55.3%	35.5%	7.8%	0.81	0.71
1 single condition	56.7%	33.1%	9.3%	Ref	
2 multimorbidity- 2 conditions	49.1%	38.5%	11.7%	1.27	0.44
3 multimorbidity- 3 conditions	45.2%	39.2%	15.7%	1.77	0.03
4 multimorbidity- 4 conditions	39.8%	36.9%	24.5%	3.05	<0.01
5 multimorbidity- 5 or more conditions	40.1%	35.1%	26.1%	3.31	<0.01
Number of condition clusters in categories					
0 no condition cluster	55.3%	35.5%	7.8%	0.74	0.58
1 single condition cluster	52.1%	37.0%	10.2%	Ref	
2 two or more condition clusters	43.9%	36.7%	19.7%	2.13	<0.01
Number of condition clusters in categories					
0 no condition cluster	55.3%	35.5%	7.8%	0.74	0.58
1 single condition cluster	52.1%	37.0%	10.2%	Ref	
2 two condition clusters	47.0%	37.3%	15.6%	1.62	0.01
3 three condition clusters	39.9%	38.4%	22.5%	2.50	<0.01
4 four or more condition clusters	41.0%	30.8%	29.6%	3.60	<0.01
Type of clusters					
Cardiopulmonary	44.3%	37.4%	18.4%	1.99	<0.01
Sensory-motor	38.3%	37.5%	25.4%	1.92	<0.01
Depression-dementia	40.3%	30.9%	30.6%	2.98	<0.01
Arthritis-osteoporosis	45.8%	36.1%	18.3%	1.38	0.04
Cancer	48.2%	36.7%	14.8%	0.84	0.35
Most commonly occurred condition combination					
1. Hypertension & arthritis	43.7%	41.8%	14.9%	0.86	0.60
2. Hypertension, arthritis, & diabetes	44.4%	41.9%	15.9%	0.93	0.87
3. Hypertension, arthritis, & cancer	54.4%	38.7%	6.5%	0.32	0.13
4. Hypertension & diabetes	44.2%	38.6%	16.7%	1.04	0.94
5. Hypertension & cancer	62.1%	36.7%	4.5%	0.22	0.03

Unweighted n=2,017

Table 3: Multiple logistic regression results

OR & p-values	Model 1	Model 2	Model 3a	Model 3b	Model 4
Age 85 and over	**1.51**	1.41	**1.46**	1.26	**2.56**
	(0.02)	(0.08)	**(0.04)**	(0.27)	**(0.04)**
Male	**1.51**	**1.53**	**1.54**	1.42	1.60
	(0.03)	**(0.03)**	**(0.02)**	(0.07)	(0.23)
No high school diploma	**2.19**	**2.11**	**2.10**	**1.84**	**3.96**
	(<0.01)	**(<0.01)**	**(<0.01)**	**(<0.01)**	**(<0.01)**
Lower English proficiency	**3.06**	**2.91**	**2.87**	2.56	**4.08**
	(0.03)	**(0.04)**	**(0.04)**	(0.11)	**(0.01)**
Limitation in mobility	**2.05**	**1.93**	**1.88**	**1.92**	1.93
	(<0.01)	**(<0.01)**	**(<0.01)**	**(<0.01)**	(0.20)
Multimorbidity	**1.77**			1.11	
	(0.01)			(0.80)	
Number of condition clusters					
Two clusters		**1.58**			
		(0.01)			
Three clusters		**2.05**			
		(<0.01)			
Four or more clusters		**2.19**			
		(<0.01)			
Number of conditions					
Two conditions			1.31		
			(0.37)		
Three conditions			1.47		
			(0.14)		
Four conditions			**2.61**		
			(<0.01)		
Five or more conditions			**2.21**		
			(<0.01)		
Type of cluster					
Cardiopulmonary cluster					**1.66**
					(0.04)
Sensory-motor cluster					1.21
					(0.24)
Depression-dementia cluster					**1.91**
					(<0.01)
Arthritis-osteoporosis cluster					1.26
					(0.21)
Cancer cluster					0.71
					(0.09)

Figure 1: Conceptual framework



Chapter 3: Role Preferences for Medical Decision-making among Older Adults with Incident Possible or Probable Dementia in the United States

Abstract

Importance: The number of older adults living with dementia is substantial in the U.S. Involving individuals with dementia in decision-making helps provide person-centered care, the best practice of care for dementia; however, role preferences for medical decision-making among individuals with mild cognitive impairment due to Alzheimer's disease or relatively early stages of dementia are largely unknown. Little is known about the types of impaired cognitive domains that are associated with role preferences for decision-making.

Objectives: To examine (1) differences in role preferences for medical decision-making among older adults with incident possible or probable dementia compared to older adults with no dementia, and (2) whether impaired memory, orientation, or executive function is associated with role preferences for medical decision-making.

Methods: A retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study.

Study sample: 1,542 older adults living in community or residential settings and free of dementia at baseline. The study sample represented approximately 27.3 million Medicare beneficiaries aged 65 and older.

Main outcome of interest: Older adults were considered to have passive role preferences for decision-making if they stated that they prefer to leave decisions up to doctors.

Results: 22.8% of older adults with incident possible or probable dementia stated they prefer a passive role in medical decision-making compared to 11.2% of older adults with no dementia ($p<0.01$). Having incident possible or probable dementia was associated with higher odds of preferring a passive role relative to not having dementia after controlling for age, gender, educational attainment, and multimorbidity (aOR=1.61, p=0.03). Impaired memory, mostly due to impaired immediate recall, was associated with higher odds of preferring a passive role (aOR for impaired memory=2.77, $p<0.01$). Impaired executive function and impaired orientation were not statistically significantly associated with passive role preferences.

Conclusions: Despite cognitive decline, the vast majority of individuals with dementia still want to participate in medical decision-making. Personal values and needs should be used in guiding health care decisions for individuals with dementia. However, individuals with incident possible or probable dementia are more likely to disengage from decision-making. Further research should evaluate how this occurs, investigating factors such as inactive coping styles, reduced self-confidence, and communication barriers.

Background

The number of older adults living with dementia is substantial and is expected to grow within the next decades in the U.S. as the population ages and the percentage of people living into very old age increases.[1] Dementia is a syndrome affecting two or more impaired cognitive domains severely enough to interfere with daily functioning.[2] In 2010, dementia affected approximately 5.1 million older adults in the U.S.[1] Alzheimer's disease (AD) is the most common cause of dementia in older adults, for about 70 percent of all dementias.[3] The population of AD among older adults is expected to nearly triple, to 13.8 million (approximately one in every seven older adults), by 2050.[1,4] Dementia impacts many aspects of well-being, functioning, and daily life, so individuals with dementia often need significant caregiving support and become heavy users of medical care and long-term services.[5,6] In 2011, 5.8 million family and unpaid caregivers provided more than 500 million hours of assistance per month to care older adults with dementia.[7] The cost of nursing home and community-based long-term care for individuals with dementia was $109 billion in 2010.[8] The growing dementia population places an enormous burden on their families and U.S. health care systems.

The needs of individuals with dementia are complex and heterogeneous, related to a combination of the stage of neurological impairment, personal health and fitness level, personal life experience,

personality and coping style, and social environment in which they live.[9] Providing person-centered care has been increasingly recognized as the best practice of care for dementia.[9,10] Brooker (2004, 2007) proposes the VIPS framework for person-centered dementia care that consists of (1) valuing people with dementia and caregivers, (2) treating people as individuals, (3) using the perspective of the person with dementia, and (4) providing a positive social environment.[11,12] Providing care that respects personhood and supports individual needs may improve their well-being and reduce disruptive behaviors.[13] Involving individuals with dementia in decision-making not only helps improve the likelihood that care meets individuals' needs and values but also can ease some burdens of caregivers, therefore potentially improving quality of life for both individuals with dementia and their caregivers.[14]

Individuals with dementia are often excluded from medical decision-making, despite growing evidence suggesting that some individuals, even in the later stages of dementia, still can express their values and needs.[15] The most likely reason for such exclusion is the concerns about impaired decision-making capacity due to dementia. However, regardless of whether or not individuals with dementia are capable of making decisions, they can still participate in decision-making by expressing their preferences and values. The existing literature indicates that individuals with dementia can comment on their own quality of life, the care they receive, and their care values and beliefs

even through the later stages of dementia.[16-19] This highlights the importance of weighing personal values and beliefs when making medical decisions with or for individuals with dementia. We need to view individuals with dementia as someone who may experience cognitive decline, but who can still experience the same feeling, thoughts, and responses like individuals without dementia do, so we should recognize that each individual with dementia may have unique experience and perspective with the care received.[9,20]

Despite the importance of involving individuals with dementia in medical decision-making, their role preferences for decision-making are poorly understood, especially for those who experience onset of dementia symptoms. Intra-individual change in cognition is considered as a more sensitive measure to detecting dementia or mild cognitive impairment (MCI) due to AD than one-time measure.[21] The evidence of worsening cognition and onset of symptoms over time are part of "Core Clinical Criteria" for probable dementia and MCI due to AD.[21] This suggests that using the incidence of dementia symptoms might be a better indicator to probable or possible dementia if longitudinal assessment is available.

Moreover, role preferences among individuals with MCI due to AD or relatively early stages of dementia are largely unknown. Most existing literature in decision-making preferences among individuals with dementia draws samples from memory clinics or medical centers. Given that dementia is often missed or delayed as a diagnosis in clinical

settings,[22] the study samples of the existing literature predominantly consist of individuals in the middle and later stages of dementia.[23,24] Although a small percentage of individuals who experience onset of dementia symptoms may be newly diagnosed with dementia, most of them are likely to be individuals whose symptoms affect one cognitive domain and are not severe enough to interfere with daily functioning (i.e., MCI due to AD which is often considered as possible dementia in research), [25-27] and individuals with dementia symptoms affected two or more cognitive domains but who do not yet have a formal diagnosis of dementia or whose symptoms are not noticeable to family and close friends (i.e., probable dementia). Furthermore, dementia symptoms are not uniform among individuals, and little research has addressed the types of impaired cognitive domains that are associated with role preferences for decision-making.

Study Aims

To address the gap in the existing literature on role preferences for decision-making among individuals with incident possible or probable dementia, this study aims to examine (1) differences in role preferences for medical decision-making among older adults with incident possible or probable dementia compared to older adults with no dementia, and (2) whether impaired memory, orientation, or executive function is associated with role preferences for medical decision-making.

Methods

Study design and data source

This was a retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study (NHATS) collected in 2011 and 2012. NHATS is a population-based longitudinal study on the late-life disability trends and trajectories of older adults living in the contiguous U.S. The weighted NHATS sample is nationally representative given that it was drawn from the Medicare enrollment file that represented 96% of persons living in the contiguous U.S. who are age 65 and over. The first round of the NHATS survey was conducted in 2011. Older adults were re-interviewed annually to track their functional status and health conditions. A stratified three-stage sampling design was used with randomly selected Medicare beneficiaries sampled with selected ZIP codes that were nested within selected counties. The probabilities of selection at each of the three stages were designed to yield equal probability samples and targeted sample sizes by age group and race and ethnicity group. Over age 85 and Black non-Hispanic groups were oversampled. Of the 12,411 Medicare beneficiaries sampled for the first wave of the NHATS, 7,609 completed the in-person interview in the first wave, and 6,056 completed the in-person interview in the first two waves. In the second wave, one-third of the older adults were randomly selected for a supplemental module on preferences for health care decision-making.

Study sample

Older adults who responded to the first two waves of NHATS and completed the supplemental module for health care decision-making were included in the initial study population (n=2,063). We excluded 22 older adults who moved to nursing homes between the first and second waves of NHATS since a large proportion of this population had missing information used for the NHATS dementia classification method (see below in Measures section). A small number of older adults who had missing responses to the health care decision-making module were also excluded (n=24). We excluded older adults who were considered to have possible or probable dementia at baseline (n=475) since the population of interest in this study was individuals who experience onset of dementia symptoms (i.e., incident possible or probable cases). We chose to focus on incident dementia to address a more homogeneous population with relatively early stages of dementia and MCI due to AD.

The final sample for this study included 1,542 older adults living in community or residential settings and free of dementia at baseline. With sample weights, the study sample represented approximately 27.3 million Medicare beneficiaries aged 65 and older in the U.S.

Conceptual framework

We outlined a conceptual framework encompassing both known and putative factors associated with individuals' role preferences in medical decision-making (**Figure 1**). We reviewed the existing literature on individuals' stated preferences in making medical decisions to find

evidence on factors related to role preferences. We also reviewed literature on dementia, the key independent variable, to identify the possible relationship between dementia and the known and putative socio-demographic and health care-related factors that were associated with role preferences in decision-making. Confounding socio-demographic variables included age, gender, race/ethnicity, educational attainment, income, marital status, and acculturation factors. We hypothesized that being older, Black, Hispanic, poorer, less educated, or an immigrant is associated with both higher odds of passive role preferences in decision-making[28-31,31-36] and higher risk of dementia.[5,37-40] Being male and married were hypothesized to be associated with higher odds of passive role preferences and lower risk of dementia.[41,42] Multimorbidity is hypothesized to be associated with both higher odds of passive role decision-making and higher risk of dementia. Relationship with providers is hypothesized to be a confounding variable—having a regular source of care is associated with higher odds of passive role preferences;[43-45] and having a third person during medical visits is associated with lower odds of passive role preferences as it is a sign that family members have more control in decision-making.[28,46]

Measures

Older adults were read a statement - “People today are faced with many decisions about their health care—for example whether to start or change a medicine. We want to know how you prefer to have doctors and

family or close friends help with decisions. Thinking about your doctors, do you prefer to…". Response categories included: (a) make decisions without much advice, (b) get their advice and then make decisions, (c) make decisions together, and (d) leave decisions up to them.[47] The role preferences for medical decision-making were categorized into three distinct roles according to the widely adapted typology proposed by Charles in 1997: (1) active role, in which individuals decide which treatment option would be most appropriate, whether with or without advice from providers; (2) collaborative role, in which individuals and providers make decisions together; and (3) passive role, in which individuals leave decisions up to providers.[48,49]

We adopted the dementia classification developed by the NHATS team.[50] Older adults were classified as none, possible, and probable dementia using a combination of information that included self-reported doctor diagnosis of AD or dementia, a score on the AD8 Dementia Screening Interview by proxy respondents, and a cognition battery on older adults' memory, orientation, and executive function.[50] Memory tests included an immediate recall of a 10-item non-semantically related word list and a delayed recall of the same list after about 5 minutes filled with distractor questions. The orientation domain was assessed by asking older adults the date (month/day/year), day of week, name of current President, and name of Vice President. Clock-drawing Test was used to assess the executive function domain. Older adults who scored

at or lower than 1.5 standard deviation below the mean score in a given domain in the cognition battery were considered as impaired in that domain.

Older adults who reported a diagnosis of dementia either by self or by proxy, older adults whose proxy respondents reported a score of 2 or higher in the AD8 interview, and older adults who had impairment in at least two domains in the cognition battery were considered to have probable dementia. Impairment in only one domain in the cognition battery was classified as possible dementia in NHATS. Individuals who were classified as possible dementia mostly likely have MCI due to AD.[25-27,50] The classification used in NHATS (possible or probable dementia vs. no dementia) was validated against the diagnosis information in the Aging, Demographics, and Memory Study (ADAMS) Wave E that was conducted in 2010.[50]

Socio-demographic variables included in the analyses were age in ten-year groups, gender, educational attainment, race and ethnicity, annual household income, marital status, and acculturation factors. Annual household income was constructed in quartiles by marital status using the imputed total income value provided on the NHATS public use file. NHATS imputed total incomes for 44% of individuals who did not provide a total income amount.[51] Cutoffs for quartiles were $10,503, $17,000, and $29,900 for unmarried older adults, and $25,000, $42,200, and $70,000 for married older adults, respectively.

Acculturation factors were measured by self-reported English proficiency and length of residence in the U.S. Older adults who speak English only or who speak English very well or well were considered to have English proficiency, whereas older adults who speak English not well or not at all were considered to not have English proficiency - as suggested in at least one published studies.[52] Length of residence was classified into three categories, including born in the U.S., born in a foreign country and moved to the U.S. before age 45, and born in a foreign country and moved to the U.S. at age 45 or older.

Multimorbidity was measured using a combination of information that included self-reported doctor diagnosis of nine common chronic diseases, self-reported sensory impairment, and the 4-item patient health questionnaire (PHQ-4) for depression and anxiety. In the first wave of the NHATS survey, older adults were asked if they had been diagnosed by medical doctors with the following diseases: heart attack, heart disease including angina or congestive heart failure, hypertension, arthritis including osteoarthritis and rheumatoid arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer. In the second wave of the survey, older adults were asked if they were newly diagnosed with the same set of diseases since the last interview. Older adults were considered to have a given disease if they reported being diagnosed in either the 1st or 2nd wave. Older adults were considered to have vision impairment if they reported blindness or reported that they do not see

well enough, even with glasses or contacts, to recognize someone across the street, to watch television across the room, or to read newspaper print. Older adults were considered to have hearing impairment if they reported deafness, or reported that they do not hear well enough, even with hearing aids, to use the telephone, to hear conversations on the radio, or to carry on a conversation in a quiet room.[53] Depression and anxiety were measured by the PHQ-4 which consists of the two-item patient health questionnaire (PHQ-2) and the two-item generalized anxiety disorder scale (GAD-2). Response sets used for assessing level of depression and anxiety were “nearly everyday” (3), “more than half the days” (2), “several days” (1), or “not at all” (0). Scores were summed across the four items and then a sum score of 6 or higher was considered as having depression and anxiety.[54]

Multimorbidity was measured in a simple count of clusters of related conditions in categories (i.e., no cluster, one cluster, and two or more clusters). We adapted a set of condition clusters from a previously published study with one additional cluster for cancer to categorize the twelve conditions that NHATS collected.[55] The clusters were: (1) cardiopulmonary cluster, including stroke, heart disease, heart attack, diabetes, high blood pressure, and lung disease; (2) sensory-motor cluster, including vision or hearing problems; (3) depression cluster; (4) arthritis and osteoporosis; and (5) cancer. Adaptation of the methods in this study was chosen over other studies in condition clustering because

(1) this set of condition clusters was shown to have better predictability on functional status and self-assessed physical health in three years compared to a simple count of coexisting conditions, (2) condition clusters were developed in a survey on which diagnosis information was self-reported, like NHATS, and (3) the broad range of conditions included in developing the condition clusters overlapped with the information in NHATS very well. Dementia was not included in the multimorbidity measure because it was considered separately.

Relationship with providers was measured in three variables. We used self-reported having a usual source of care and self-reported seeing the usual source of care in the last year to measure if there was a consistent relationship between an older adult and her/his usual source of care. Older adults were asked if there was a third person sitting in during doctor visits, and it was used to measure if there is a third person involved in the relationship with providers.

Analyses

We used the Wald test statistics to compare the differences between older adults who had incident possible or probable dementia and those with no dementia in age, gender, educational attainment, race/ethnicity, annual household income, marital status, acculturation factors (language proficiency and length of residence), multimorbidity, and relationship with providers (self-reported a usual source of care, saw the doctor in the last year, and a third person during medical visits). We

also examined the difference in the proportions of passive role preferences by (1) dementia status and (2) impaired cognitive domains, using the Wald test statistics.

The regression analyses in the study focused on comparing people who preferred a passive role against others who preferred either an active or a collaborative role in decision-making, because this analysis built upon previous work by Wolff and Boyd (2015), which categorized decision-making preferences as leaving all decisions up to the doctor (i.e., passive) versus others.[47] As part of sensitivity analyses, we used regression models to compare people who preferred an active role against those who preferred a collaborative role, and we found no significant difference between the incident possible or probable dementia group and the no dementia group after adjusting for confounding variables.

We constructed multiple logistic regression models to determine whether preferences for a passive role in decision-making were different between the incident possible or probable dementia group and the no dementia group after controlling for a set of confounding variables that were statistically significant in bivariate analyses (Model 1). Using the backward elimination process with cut-off p-value of 0.05 as guidance, age, gender, educational attainment and multimorbidity were included in the multiple regression models. The basic model for multiple logistic regression model was specified as: $Y = \beta_0 + \beta_1 X^{\textit{incident dementia}} + \beta_2 X^{\textit{age, gender, educational attainment, and multimorbidity}} + \epsilon$. To better understand if impairment in a

particular cognitive domain is statistically significantly associated with passive role preferences, we constructed multiple regression models to examine the relationship between preferences for a passive role and cognitive domains that are impaired (Model 2a and Model 2b). As part of sensitivity analyses, we also included interaction terms between cognitive domains in the main model given that some literature implied that decisional capacity is strongly associated with both of executive function and memory. However, none of the interaction terms tested showed statistical significance, so we did not include interaction terms in the multiple regression models.

The analyses were conducted in Stata SE 11 (StataCorp, College Station, TX). We used analytic weights to account for the complex sampling strategy and the svy commands in Stata to produce standard errors on the estimates. The subpop option in Stata was used to produce point and variance estimates for the study population that is a subset of total population of NHATS. A significance level of $\alpha = 0.05$ was used for analyses.

Results

The study population represented 27.3 million adults ages 65 or older who did not have possible or probable dementia in 2011 and were living in community or residential settings in the U.S. Over half of them were between 65 and 74 (59.8%), 31.5% were between 75 and 84, and

8.7% were older than age 85. Females accounted for 57.7% of the study population. The major race and ethnicity was White, non-Hispanic (83.7%), followed by Black, non-Hispanic (7.1%), Hispanic (5.1%), and others (4.1%). Eight and a half percent of the study population experienced onset of possible or probable dementia in the following year (**Table 1**).

Older adults with incident possible or probable dementia were different from those with no dementia in many socio-demographic characteristics and health-care related factors. Higher proportions of older adults with incident possible or probable dementia were age 75 or older, less educated, at the lowest two quartiles of income, widowed, and immigrants. Multimorbidity was more common among the incident possible or probable dementia group than the no dementia group. Having a third person sitting in medical visits was also more common among older adults with incident possible or probable dementia (**Table 1**).

Among older adults with incident possible or probable dementia, 72.1% were considered to have possible dementia and 27.9% were considered to have probable dementia. The most prevalent impaired cognitive domain among possible dementia was memory (58.2%), followed by executive function (29.9%) and orientation (11.9%). Forty-four percent of persons with probable dementia had a diagnosis of AD or dementia from a medical doctor, and 23.2% of them were reported as having dementia symptoms by their proxy respondents. The most

prevalent combination of impaired cognitive domains among probable dementia was memory and orientation (18.0%), followed by memory and executive function (8.2%), and orientation and executive function (6.0%). A very small percentage of persons with probable dementia living in community or residential settings were impaired in all domains that were assessed (0.4%) (**Table 2**).

The majority of older adults with incident probable or possible dementia stated that they prefer an active or collaborative role in decision-making, as did older adults with no dementia. However, a higher proportion of older adults with incident probable or possible dementia stated that they prefer a passive role in medical decision-making compared to older adults with no dementia (22.8% vs. 11.2%, respectively, $p<0.01$). Of the three cognitive domains, individuals who were impaired in memory, both based on immediate and delayed recall, were more likely to prefer a passive role in decision making compared to individuals with no impairment in memory (29.7% vs. 12.3%, $p<0.01$ for overall memory; 31.0% vs. 12.3%, $p=0.02$ for immediate recall; 25.3% vs. 11.6%, $p=0.01$ for delayed recall). Impaired executive function and impaired orientation were not statistically significantly associated with passive role preferences (**Table 3**).

Results from multiple logistic regression models were consistent with the findings in bivariate analyses. Having incident possible or probable dementia was associated with higher odds of preferring a

passive role in decision-making compared to no dementia after controlling for age, gender, educational attainment and multimorbidity (aOR=1.61, p=0.03, Model 1). Impaired memory, mostly due to impaired immediate recall, was associated with higher odds of preferring a passive role (aOR for impaired memory =2.77, p<0.01, Model 2a; aOR for impaired immediate recall=2.59, p<0.01; aOR for impaired delayed recall=1.39, p=0.17, Model 2b). Impaired executive function and impaired orientation were not statistically significantly associated with passive role preferences (aOR=0.68, p=0.43 for executive function, aOR=0.70, p=0.40 for orientation, Model 2a) (**Table 4**).

Discussion

Drawing upon data from a nationally representative survey on the elderly population in U.S., we find that older adults living in community or residential settings are more likely to state that they prefer to leave decisions up to providers if they have incident possible or probable dementia compared to older adults with no dementia, although the vast majority still state that they prefer an active or collaborative role in medical decision-making. We also find that impaired memory, but not executive function or orientation, is statistically significantly associated with passive role preferences among older adults. Our findings illustrate that impaired decision-making capacity, as indicated as poorer memory, may be a predictor of passive role preferences for decision-making.

Engaging individuals with dementia to make medical decisions potentially promotes person-centered care and quality of life for both individuals and caregivers, and our study findings provide a promising perspective as the majority of older adults with incident possible or probable dementia state that they prefer an active or collaborative role in decision-making. This agrees well with the existing literature that suggests most individuals with dementia or MCI due to AD still want to participate in decision-making.[23,24] We also find the proportion of individuals who prefer a passive role in our study is similar to other studies of patients with MCI due to AD or the early stages of dementia.[24] However, the proportion of individuals who prefer a passive role in this study is higher than that in another U.S. study that drew samples from patients in the middle stages of dementia in a memory clinic,[23] which is contradictory to the evidence that suggests more severe dementia is associated with higher odds of passive role preferences.[56] Although the relatively small sample sizes, the differences in individuals' characteristics and how questions about role preferences in decision-making were structured make the head-to-head comparison difficult, the differences we observed seem to indicate that there might be some clinical characteristics or individuals' experience related to MCI due to AD or early stages of dementia that are associated with higher odds of passive role preferences. For example, inactive coping style is frequently seen among this group,[57] and it is associated with passive role

preferences.[31] Further research on why the passive role is more likely to be preferred among individuals with MCI due to AD or early stages of dementia is needed.

Our findings illustrate that decision-making capacity may be a predictor of preferences for decision-making. A previous study indicates that individuals' confidence in their decision-making capacity could predict preferences in decision-making.[58] Individuals are aware of whether or not they recall correct episodic memory, even through the middle stages of dementia.[59] It is plausible that the awareness of incorrect recall may decrease individuals' confidence in decision-making capacity, thus make them more likely to prefer a passive role in decision-making for individuals with dementia-related symptoms, regardless of whether diagnosis of dementia has been made.

We find that older adults who have impaired episodic memory have higher odds of preferring a passive role compared to others whose episodic memory is not impaired. Episodic memory is the ability to learn and retain new information, and is assessed via the immediate and delayed recall tests in NHATS. Research on decisional capacity - measured based on the established consent standards of understanding, reasoning, appreciation, and communication- suggests that individuals with dementia due to AD often show deficits in understanding.[60] They often have difficulty understanding treatment situations, such as pros and cons of treatments.[61] Understanding treatment situations relies on

facts and is related to conceptualization, semantic memory, and short-term episodic memory.[61] We find that impaired immediate recall, but not impaired delayed call, is associated with passive role preferences. This could be due to the fact that impaired immediate recall indicates more memory impairment as it indicates impairment in encoding new information, whereas impaired delayed recall indicates impairment in encoding, storing, and retrieval information – more complex processing. Executive function is also strongly associated with decision-making capacity,[62] as it allows individuals to weigh different factors in decision-making and to provide reasons for treatment decisions. We do not find that executive dysfunction is associated with passive role preferences; however, this could be due to low sensitivity of the test used, the Clock Drawing Test, in detecting early stages of dementia.[63] Older adults with incident probable or possible dementia in our study are likely to have normal clock drawing results as the majority of them likely have MCI due to AD.

This study is novel because the study population is drawn from a nationally representative population-based survey among community-dwelling older adults. The use of a cognition battery in addition to self-reported medical diagnosis and proxy-reported AD8 allows us to assess a broad spectrum of cognitive deficits among older adults. The study population of interest is older adults who experience onset of dementia symptoms that are not severe enough to be noticed by family members or

to be diagnosed by medical doctors – which is the group whose preferences for decision-making is largely unknown given that the existing literature is mostly based on symptomatic and more severe patients who seek medical care at clinics.[24,56,58] Moreover, this study uses older adults with no dementia as a comparison group, allowing better understanding of incident dementia in relation to role preferences in decision-making among older adults with adjustment to other confounding factors, such as age and educational attainment, which is another improvement from previous studies.[24,56,58]

This study has several limitations. First, we use results from a cognition battery to identify older adults with incident possible or probable dementia. This approach likely leads to the inclusion of some individuals with cognitive impairment other than dementia and some cognitive impairment may be transient. However, the number of individuals with cognitive impairment who are not demented is expected to be small because the cognitive domains that NHATS covered are those that would show declines starting in the early stages of dementia due to AD.[27] Secondly, there is only one question on preferences for participating in health care decision-making. However, the question is purposefully designed to focus on the entire care experience that is very relevant to older adults as the majority of them have co-existing conditions besides dementia. Lastly, this is a cross-sectional study, so a

causal relationship between incident dementia or severity of dementia and role preferences in decision-making cannot be assessed.

Implication for research and practices

Providing person-centered care is considered to be the best practice of care for individuals with dementia as each individual with dementia has complex needs and unique perspective to the care they received. Person-centered care helps care align with individuals' needs and support individuals with dementia do the things that mean the most for them. Values, beliefs, and preferences of individuals with dementia have been increasingly recognized as important factors to consider when making decisions on caring for them. Despite cognitive decline, a growing number of studies suggest that these individuals can still express their values and needs even through the later stages of dementia. Our findings also support their involvement in decision-making as we find that the majority of individuals with incident probable or possible dementia want to participate in decision-making.

One particular challenge of involving individuals with dementia in decision-making is that many of them may experience deficits in language function, especially in the later stages of dementia, which makes it difficult to express their values and needs. Caregivers and providers often express frustration that they cannot understand what individuals with dementia are trying to express. Consequently, individuals with dementia often stop expressing in order to avoid

frustration from others.[20] Nevertheless, research has demonstrated that individuals with dementia can express their view on quality of life using a picture card exercise approach.[64] Using a picture card exercise approach, individuals with dementia were shown a set of simple picture cards that represent key quality of life indicators and asked to place each card on marked papers according to its importance. Future research on designing a simple yet effective way of communicating with individuals with dementia about personal values and preferences for health-related quality of life or quality of care, particularly with those who experience language loss, would be potentially beneficial to encourage them involve in decision-making.

Our study findings also point out potential target groups for intervention that encourages participation in decision-making as we find that individuals with incident possible or probable dementia are more likely to prefer a passive role in decision-making. Possible factors contributing to this tendency include less active coping styles, impaired decision-making capacity, and communication barriers, and, fortunately, these factors are amenable to some extent. Future development of decision aids that remind patients of their health situation and pros and cons related to treatment options in an accessible form might be beneficial to older adults with incident dementia to overcome difficulties in understanding treatment situations or might help them express their

values and preferences, and may encourage them more actively participate in medical decision-making.

Conclusion

The needs of individuals with dementia are complex and heterogeneous, and the best practice of care for individuals with dementia should be person-centered. Despite cognitive decline, the vast majority of individuals with dementia still wants to participate in medical decision-making and are capable of expressing their needs and values. Personal values and needs should be used in guiding health care decisions for individuals with dementia. However, individuals with incident possible or probable dementia are more likely to disengage from decision-making. Further research should evaluate how this occurs, investigating factors such as inactive coping styles, reduced self-confidence, or communication barriers.

Table 1: Socio-demographic characteristics, multimorbidity, and relationship with providers by dementia status among older people who did not have dementia in 2011 in the U.S

Column %	All	Dementia Status		Incident dementia vs. no dementia p-value*
		Incident possible or probable dementia	No dementia	
Total in million	27.3	2.3	25.0	
%		8.5%	91.5%	
Age in category (R1)				
Age 65-74	59.8%	38.1%	61.8%	<0.01
Age 75-84	31.5%	37.3%	31.0%	
Age 85+	8.7%	24.7%	7.2%	
Female	57.7%	53.3%	58.1%	0.28
Male	42.3%	46.7%	41.9%	
Race and ethnicity				
1 White, non-Hispanic	83.7%	77.2%	84.3%	0.13
2 Black, non-Hispanic	7.1%	8.8%	6.9%	
3 Hispanic	5.1%	10.1%	4.7%	
4 Others	4.1%	3.9%	4.1%	
High school diploma	82.6%	61.6%	84.6%	<0.01
Less than high school	17.4%	38.4%	15.4%	
Household income v3				
1 1st lowest quartile	16.0%	30.3%	14.7%	<0.01
2 2nd quartile	22.5%	28.6%	21.9%	
3 3rd quartile	23.8%	18.4%	24.3%	
4 4th quartile	37.7%	22.7%	39.1%	
Marital status				
1 Married/Living with a partner	61.3%	52.8%	62.1%	0.02
2 Widowed	23.0%	34.0%	21.9%	
3 Separated/Divorced/Never married	15.7%	13.2%	16.0%	

Column %	All	Dementia Status		Incident dementia vs. no dementia p-value*
		Incident possible or probable dementia	No dementia	
Length of stay in U.S.				
1 U.S. born	91.2%	81.8%	92.1%	<0.01
2 Foreign born and move to U.S. before age 45	7.3%	13.7%	6.8%	
3 Foreign born and move to U.S. at or after age 45	1.4%	4.5%	1.1%	
Not have English proficiency	0.9%	3.0%	0.7%	0.13
English proficiency	99.1%	97.0%	99.3%	
Number of condition clusters (dementia not counted)				
0 no condition cluster	7.9%	10.1%	7.7%	<0.01
1 single condition cluster	27.2%	14.4%	28.4%	
2 two or more condition clusters	64.8%	75.6%	63.8%	
Not have usual source of care	4.2%	5.2%	4.2%	0.61
Have usual source of care (USC)	95.8%	94.8%	95.8%	
Not see USC last year	6.5%	5.7%	6.5%	0.65
Saw USC last year	93.5%	94.3%	93.5%	
No third person sit in visits	69.8%	46.2%	72.0%	<0.01
Third person sit in visits	30.2%	53.8%	28.0%	

*Unweighted n=1,542

Table 2. Cognitive function in 2012 among older people who have incident possible or probable dementia in 2012 in the U.S.

	Incident possible or probable dementia
Total in million (%)	2.3 (8.5%)
Cognitive function	
Possible dementia	72.1%
Impaired memory alone	58.2%
Impaired executive function alone	29.9%
Impaired orientation alone	11.9%
Probable dementia *	27.9%
Doctor's diagnosis	44.1%
Meet AD8 criteria	23.2%
Impaired memory and orientation	18.0%
Impaired memory and executive function	8.2%
Impaired orientation and executive function	6.0%
Impaired memory, orientation and executive function	0.4%
Impaired cognitive domains *	
Executive function - clock drawing	28.2%
Memory- 10 words recall	57.1%
Orientation- date/time	19.1%

*Unweighted n=169

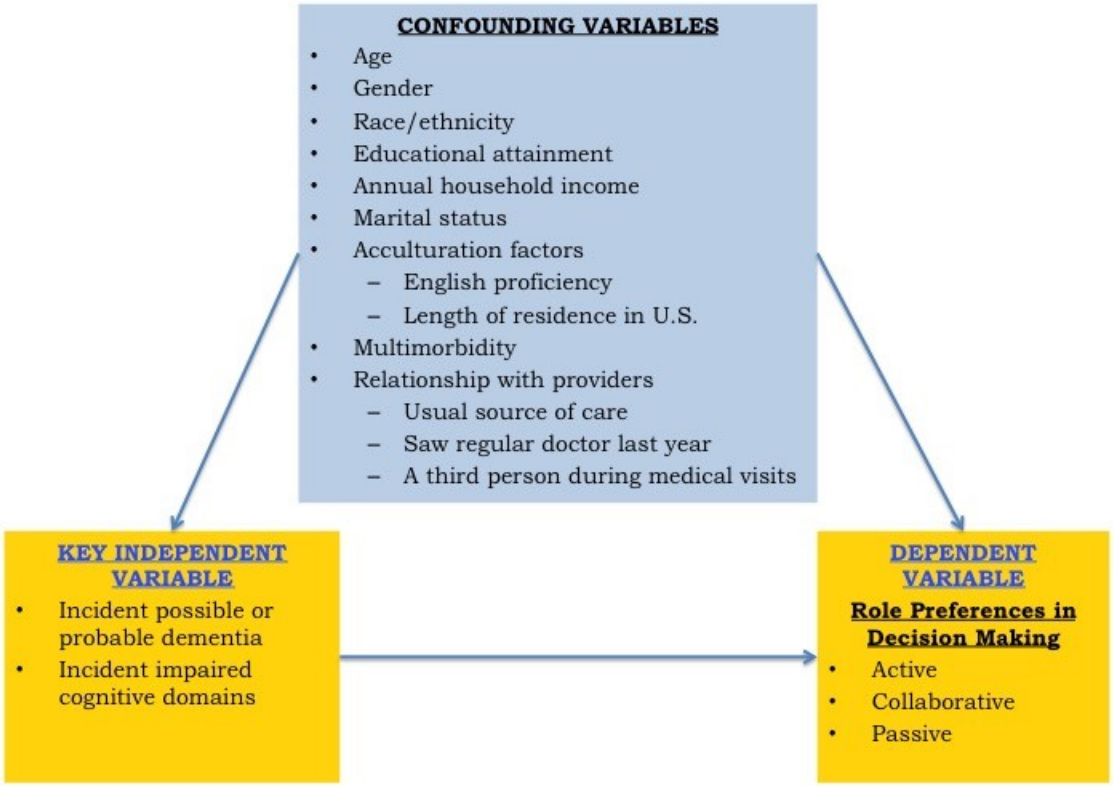
Table 3: Role preferences in medical decision-making by dementia status among older people who did not have dementia in 2011 in the U.S.

Row %	Active	Collaborative	Passive	Passive vs. others p-value*
Total in million (%)	13.5	11.5	3.3	
%	49.4%	38.5%	12.1%	
No dementia	49.2%	39.6%	11.2%	<0.01
Incident possible or probable dementia	50.7%	26.5%	22.8%	
Cognitive domains				
Executive function - clock drawing				
Impaired	46.6%	29.1%	24.3%	0.08
Not impaired	47.7%	38.6%	13.6%	
Memory- 10 words recall both delayed and immediate				
Impaired	40.9%	29.4%	29.7%	<0.01
Not impaired	48.5%	39.2%	12.3%	
Memory- 10 words **immediate** recall				
Impaired	38.1%	30.9%	31.0%	0.02
Not impaired	48.8%	39.0%	12.3%	
Memory- 10 words **delayed** recall				
Impaired	42.0%	32.7%	25.3%	0.01
Not impaired	49.0%	39.4%	11.6%	
Orientation- dates/naming				
Impaired	37.2%	36.9%	25.9%	0.54
Not impaired	48.4%	38.3%	13.3%	

Table 4: Multiple logistic regression results

aOR (p-values)	Model 1*	Model 2a **	Model 2b **
Age 85+	**1.82** **(<0.01)**	**1.72** **(<0.01)**	**1.70** **(0.01)**
Male	**1.50** **(<0.05)**	**1.49** **(0.06)**	**1.47** **(0.06)**
No high school diploma	**2.24** **(<0.01)**	**2.21** **(<0.01)**	**2.17** **(<0.01)**
Two or more condition clusters	**2.14** **(<0.01)**	**2.15** **(<0.01)**	**2.01** **(<0.01)**
Incident possible or probable dementia	**1.61** **(0.03)**		
Impaired cognitive domain- executive function		0.68 (0.43)	0.64 (0.38)
Impaired cognitive domain- orientation		0.70 (0.48)	0.62 (0.36)
Impaired cognitive domain- memory		**2.77** **(<0.01)**	
Impaired cognitive domain- memory **immediate** recall			**2.59** **(<0.01)**
Impaired cognitive domain- memory **delayed** recall			1.39 (0.17)

Figure 1: Conceptual framework



Chapter 4: The Association between Multimorbidity Patterns and Experiences with Treatment Burden among Older Adults in the United States

Abstract

Importance: Older adults with multimorbidity are particularly vulnerable to treatment burden. Treatment burden is associated with increased risk of non-adherence to treatment regimens, worse functional status, and adverse events. Identifying individuals with multimorbidity who are overwhelmed by their treatment plan is an important step in moving toward providing person-centered care. However, little is known about the association between multimorbidity patterns and treatment burden.

Objective: To examine the association between multimorbidity patterns and treatment burden.

Methods: A retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study.

Study sample: 2,041 older adults living in community or residential settings in the United States. The study sample represented approximately 33.4 million Medicare beneficiaries aged 65 and older.

Main outcomes of interest: Older adults were asked to reflect on four experiences of treatment burden: difficulty in self-managing health, difficulty experienced by family or close friends in managing older adults' health, non-adherence to self-management or treatment regimen, and

feeling that managing health is overwhelming. Older adults' experiences were defined as treatment burden if he/she reported a given experience occurs "sometimes" or "often". In addition to the four dichotomized measures, we constructed a composite measure to identify older adults who reported that one or more of the four experiences occur "sometimes" or "often".

Results: Older adults with three or more condition clusters were statistically significantly more likely to experience any treatment burden than those with one condition cluster (45.1% vs. 34.8%, unadjusted OR=1.5, $p<0.01$). In bivariate analyses, we found that having three or more condition clusters was associated with higher odds of each experience of treatment burden but not difficulty experienced by family and close friends. However, having three or more condition clusters was not associated with higher odds of treatment burden after accounting for age, gender, marital status, educational attainment, depressive symptoms, and functional status.

Conclusions: Better understanding of the burden associated with following required self-management activities and adhering to treatment regimens among older adults with multimorbidity is important. Our findings suggest that having coexisting conditions that are unrelated, i.e. in multiple clusters, may exacerbate treatment burden of older adults with multimorbidity. Moreover, other factors such as functional status and psychological factors also affect whether or not older adults perceive

managing their health as burden. In clinical settings, assessing individuals' treatment burden over time, identifying individuals who have significant treatment burden, and then modifying their treatment plans to alleviate treatment burden are important steps toward providing person-centered care.

Background

Older adults living with multimorbidity represent a large and growing segment of the elderly population in the United States (U.S.).[1,2] Multimorbidity is defined as the coexistence of two or more chronic conditions – a definition preferred by the U.S. department of Health and Human Services.[3] People with multimorbidity are at higher risk of adverse health outcomes and poor quality of care.[4-12] Person-centered care is thought to be the best practice for caring for multimorbidity.[13] Understanding how to deliver person-centered care to the multimorbidity population is regarded as a significant challenge and opportunity for clinicians, researchers, and policy makers.[10]

Identifying individuals who are overwhelmed by their treatment plan is an important step in moving toward providing person-centered care; however, how treatment burden varies among the multimorbidity population is poorly understood. Treatment burden can be defined as the workload of health care and its impact on individual functioning and well-being.[14] Time and energy demands due to treatment and self-management activities are often considered as workload. Individuals with multimorbidity are particularly vulnerable to treatment burden as they are often asked by providers to follow complex treatment regimens, lifestyle modifications, and home monitoring, i.e. more workload, in order to maintain health at an optimal level.[15] The direct adverse consequences on functioning of multimorbidity reduce individuals' ability to take on

work, thus further intensify treatment burden. Existing literature on individuals with single conditions suggest that individuals who experience treatment burden are at increased risk of non-adherence to treatment regimens and adverse events, such as hospitalization.[16-18] Greater treatment burden over time is associated with worse mental health, physical health, and individual-reported quality of care among individuals with multimorbidity.[15]

Treatment burden is a multi-dimensional construct and there is currently no gold-standard on how to best measure it among the multimorbidity population.[15,19,20] Previous qualitative studies on chronic conditions suggest that treatment burden consists of four major interrelated components. These are financial burden, time and travel burden, medication management burden, and health care access burden.[21,22] Individuals with multimorbidity may be more vulnerable to financial burden due to significant costs of multiple treatment and frequent provider consultation. Time and travel burden may also be particularly problematic among older adults with multimorbidity due as they often require multiple appointments to different providers and have limited functional status. The need to take multiple medications and the inconvenience associated with organizing and arranging medications are likely to result in medication management burden for individuals with multimorbidity. Individuals with multimorbidity are also likely to struggle with health care access burden due to the lack of care coordination

across multiple providers. It is important to emphasize that these four components of treatment burden are closely connected and often occur in cycles.[21] For example, the lack of coordination across multiple providers (health care access burden) may lead to redundant testing (travel and time burden) and polypharmacy (medication management burden), which may also place strains on financial resources (financial burden). Individuals may delay treatment or skip follow-up visits because of financial burden, and so on. Inter-relatedness of these four components makes it difficult to distinguish them in assessing treatment burden.

Measures for multimorbidity are evolving with the goal of improving how best to differentiate the vast clinical heterogeneity that the multimorbidity population shares. One of the most commonly used measures is a simple count of coexisting chronic conditions based on medical diagnosis.[23,24] This approach provides a simple analytical tool, but addresses very limited variation in the complexity or interaction among coexisting conditions. To differentiate patterns of how conditions are naturally clustering, another measure uses a simple count of condition clusters to measuring multimorbidity.[25-29] The literature suggests that this approach may have better predictability on functional status and self-assessed physical health in three years compared to a simple count of coexisting conditions.[26] In a previous study, we also found that a simple count of condition clusters is a useful way to

understand the variation in preferences for shared decision-making among older adults with multimorbidity.

Despite the advantage of measuring multimorbidity in condition clusters, little existing literature on treatment burden and multimorbidity looks beyond a simple count of conditions. Treatment burden is generally expected to be greater with increased number of coexisting chronic conditions as competing demands on individuals' resources are likely to occur,[15,30] yet a recent study finds that the number of chronic conditions is not associated with treatment burden.[31] Conversely, some coexisting conditions require related self-management activities (for example, diet and exercise plans for diabetes and for hypertension), which may not greatly increase treatment burden when managing these conditions concurrently.[32] Although a few studies have examined the types or combinations of comorbidities in relation to self-management adherence for single diseases, such as diabetes,[32] little is known about the association between patterns of multimorbidity and treatment burden among the multimorbidity population.

Study Aims

Recognizing the great variation in multimorbidity patterns and seeking to address the literature gap on treatment burden among the multimorbidity population, this study seeks to provide a comprehensive examination in the relationship between different multimorbidity

patterns and treatment burden among older adults in the U.S. We focus on older adults' experiences of treatment burden on their entire care experiences as it has wide applicability to multimorbidity. Due to the inter-relatedness of the four components of treatment burden, we assess treatment burden in a number of general measures (i.e., not specific to each of the four components) which provides a broader yet relevant aspect of treatment burden among the multimorbidity population. The objective of this study is to examine the association between patterns of multimorbidity and treatment burden among older adults in U.S., using nationally representative data.

Methods

Study design and data source

This was a retrospective cross-sectional study using data from the first two waves of the National Health and Aging Trends Study (NHATS), collected in 2011 and 2012. NHATS is a population-based longitudinal study on the late-life disability trends and trajectories of older adults living in the contiguous U.S. The weighted NHATS sample is nationally representative given that it was drawn from the Medicare enrollment file that represented 96% of persons living in the contiguous U.S. who are age 65 and over. Older adults were re-interviewed annually to track their functional status and health conditions. A stratified three-stage sampling design was used with randomly selected Medicare beneficiaries sampled with selected ZIP codes that were nested within selected counties. The

probabilities of selection at each of the three stages were designed to yield equal probability samples and targeted sample sizes by age group and race/ethnicity group. Age 85 and older and non-Hispanic Black groups were oversampled. Of the 12,411 Medicare beneficiaries sampled for the first wave of the NHATS, 7,609 completed the in-person interview in the first wave, and 6,056 completed the in-person interview in the first two waves.[33] In the second wave, one-third of the older adults were randomly selected for a supplemental module on treatment burden.

Study sample

Older adults who responded to the first two waves of NHATS and completed the supplemental module on treatment burden in the second wave were included in the initial study population (n=2,063). We excluded 22 older adults who moved to nursing homes between the first and second waves of NHATS since a large proportion of this population had missing information used for the NHATS dementia classification method (see below in Measures section). Thus the final sample for this study included 2,041 older adults living in community or residential settings who completed the supplemental module on treatment burden in the second wave. With sample weights, the study sample represented approximately 33.4 million Medicare beneficiaries aged 65 and older in the U.S.

Conceptual framework

We relied on a conceptual framework that was built upon the existing framework of treatment burden proposed by Sav et al (2013) and Eton et al (2015) (**Figure 1**).[21,22] The proposed framework also encompassed both the known and putative factors associated with treatment burden drawing from the existing literature that focuses on single disease populations, [18,32] or specific aspects of burden like perceived task difficulty.[15] First, multimorbidity represents the workload that individuals must do to care for their health as multimorbidity patterns, described as the number, type, and inter-relatedness of coexisting conditions, has direct impact on the amount of treatment regimens and self-management activities that are required. Age, gender, race/ethnicity, educational attainment, annual household income, and marital status were viewed as confounding variables in the relationship between conditions and treatment burden.[15,18,32] Cognitive functions, functional status, and depressive symptoms are also confounding variables as they are considered as barriers to self-management and home monitoring,[32,34] and they are also associated with multimorbidity.[6,7] Family involvement in health care activities is another confounding variable. It is common that family and close friends help older adults navigate health care system and perform self-management activities.[35] Family involvement in health care activities may alleviate treatment burden for the persons they assist;[36] however, family and close friends providing helps in health care activities may result in burden to

both parties as most individuals do not want to be viewed as burdensome to their family and close friends.[37] In this study, we hypothesized that family involvement in health care activities has a net positive effect on treatment burden.

Measures

Older adults' experiences of treatment burden on their entire care experiences related to managing their health were used to assess treatment burden. Older adults were read a statement –" People today are asked by their doctors and other health care providers to do many things to stay healthy or treat health problems -- for example, manage medicines, get tests and lab work done, watch weight and blood pressure, or have yearly exams." They were asked "how do you usually handle theses things?" Responses categories included "handle these things mostly by self", "handle them together with family and close friends", "family or close friends mostly handle these things", and "it varies". They were then asked to reflect on some or all of the following four experiences, depending on their responses on who handles these things. These experiences were (a) how often are the things you are asked to do to stay healthy or treat health problems hard for you to do? –which measured difficulty in self-managing health; (b) how often are these things difficult for your family or close friends to handle? -which measured difficulty experienced by family or close friends in managing older adults' health; (c) how often do these things that you are asked to

do to stay healthy or treat a health problem get delayed or not get done?- which measured non-adherence to self-management or treatment regimens, a likely outcome of treatment burden; and (d) how often do you feel that doctors and other health care providers ask you to do too much to stay healthy or treat health problems?- which measured whether sample persons feel overwhelmed by managing health. The responses categories included “never”, “rarely”, “sometimes”, and “often”.

For older adults who reported “handing these things mostly by self”, they were asked to reflect on (a) difficulty in self-managing health, (c) non-adherence to self-management or treatment regimens, and (d) feeling that managing health is overwhelming. For older adults who reported “family or close friends mostly handle these things”, they were asked to reflect on (b) difficulty experienced by family or close friends in managing older adults’ health, (c) non-adherence to self-management or treatment regimens, and (d) feeling that managing health is overwhelming. Older adults who reported ““handle them together with family and close friends”, and “it varies” were asked to reflect on all of the four experiences. Older adults’ experience was defined as treatment burden if he/she reported a given experience occurs “sometimes” or “often”. The four experiences were treated as independent dichotomized measures and were examined independently in analyses. In addition, we also constructed a summary measure – older adults who reported that

one or more of the four experiences occurs “sometimes” or “often” were identified as someone who experience any treatment burden.[31]

Multimorbidity was collected from a combination of information that included self-reported doctor diagnosis of nine common chronic diseases and self-reported sensory impairment.[38] Older adults were asked if they had been diagnosed by medical doctors with the following diseases: heart attack, heart disease including angina or congestive heart failure, hypertension, arthritis including osteoarthritis and rheumatoid arthritis, osteoporosis, diabetes, lung disease, stroke, and cancer. Older adults were considered to have vision impairment if they reported blindness or reported that they do not see well enough, even with glasses or contacts, to recognize someone across the street, to watch television across the room, or to read newspaper print. Older adults were considered to have hearing impairment if they reported deafness, or reported that they do not hear well enough, even with hearing aids, to use the telephone, to hear conversations on the radio, or to carry on a conversation in a quiet room.[39]

We used a simple count of clusters of related conditions to measure multimorbidity patterns. We adapted a set of condition clusters from a previously published study with one additional cluster for cancer to categorize the eleven conditions stated above.[26] The clusters were: (1) cardiopulmonary cluster, including stroke, heart disease, heart attack, diabetes, high blood pressure, and lung disease; (2) sensory-motor

cluster, including vision or hearing problems; (3) arthritis-osteoporosis; and (4) cancer. Adaptation of the method in this study was chosen over other studies in condition clustering because (1) this set of condition clusters was shown to have better predictability on functional status and self-assessed physical health in three years compared to a simple count of coexisting conditions, (2) condition clusters were developed in a survey on which diagnosis information was self-reported, like NHATS, and (3) the broad range of conditions included in developing the condition clusters overlapped with the information in NHATS very well. We did not include depression and dementia in measuring multimorbidity as the literature suggested that dementia and depressive symptoms are likely to be possible confounding variables, thus they were considered separately from multimorbidity.[32,34]

Depressive symptoms were measured by the PHQ-4, including the two-item individual health questionnaire (PHQ-2) and the two-item generalized anxiety disorder scale (GAD-2). Response sets used for assessing level of depressive symptoms were “nearly everyday” (3), “more than half the days” (2), “several days” (1), or “not at all” (0). Scores were summed across the four items and then a sum score of 6 or higher was considered to have depressive symptoms.[40]

We adopted the dementia classification developed by the NHATS team.[38] Older adults were classified as none, possible, and probable dementia using a combination of information in NHATS that included

self-reported doctor diagnosis of Alzheimer's disease or dementia, a score on the AD8 Dementia Screening Interview by proxy respondents, and a cognition battery on older adults' memory, orientation, and executive function[38]. Older adults who scored at lower than 1.5 standard deviation below the mean score in a given domain in the cognition battery were considered as impaired in that domain. Older adults who reported a diagnosis of dementia either by self or by proxy, persons whose proxy respondents reported a score of 2 or higher in the AD8 interview, and persons who tested impairment in at least two domains in the cognition battery were considered to have probable dementia. Impairment in only one domain in the cognition battery was classified as possible dementia in NHATS. Individuals who were classified as possible dementia mostly likely have mild cognitive impairment due to Alzheimer's disease.[38,41,42]

Self-reported needing help or difficulty with self-care activities, mobility, and household tasks were used to measure functional status. Older adults were asked how often they performed self-care activities, including eating, getting cleaned up, using toilet, and getting dressed, and mobility including getting inside, outside of house, and getting out of bed, without help in the last month.[43] An older adult was considered to have limitation in self-care activities or mobility if he/she reported having problems performing at least one activity in self-care activities or mobility without help of any person.[44] They also were asked whether they had help doing household tasks including doing laundry, shopping, preparing

hot meals, handling banking and bills, and tracking medications in the last month. Household activities limitation was identified if an older adult reported having difficulty doing at least one household tasks independently or having someone to do for or to do with for at least one household tasks because of health reasons.[45]

We used receiving help with medical visits as a proxy measure to family involvement in health care activities. Older adults who reported that they had seen their regular doctors in the past year and that someone sat with them during the visit were considered as receiving help with medical visits.

Socio-demographic variables included in the analyses were age in ten-year groups, gender, educational attainment, race and ethnicity, annual household income, and marital status. Annual household income was constructed in quartiles by marital status using the imputed total income value provided on the NHATS public use file. NHATS imputed total incomes for 44% of individuals who did not provide a total income amount.[46] Cutoffs for quartiles were $10,503, $17,000, and $29,900 for unmarried older adults, and $25,000, $42,200, and $70,000 for married older adults, respectively.

Analyses

Descriptive analyses were conducted to explore differences in socio-demographic characteristics, health status, and family involvement by multimorbidity patterns. Wald tests were used to test statistical

significance. We conducted simple and multiple regression models to examine the strength and magnitude of multimorbidity patterns of older adults in relation to treatment burden. Since treatment burden, the key dependent variables, were measured in four independent dichotomized variables and one summary variable, five sets of parallel logistic regression models were fitted – one using difficulty in self-managing health as dependent variable (Model 1), one using difficulty experienced by family or close friends in managing older adults' health as dependent variable (Model 2), one using non-adherence to self-management or treatment regimens as dependent variable (Model 3), one using feeling that managing health is overwhelming as dependent variable (Model 4), and one using experience of any treatment burden, the summary measure, as dependent variable (Model 5). In the multiple regression models, we used having one cluster of related conditions as the reference group for multimorbidity because we hypothesized that having multiple clusters of related conditions is associated with greater treatment burden compared to having conditions that fall into the same cluster and share related self-management activities. The confounding variables included in the multiple regression models were selected using backward elimination process with cut-off value of 0.05 as guidance, and they were age, gender, marital status, educational attainment, depressive symptoms, limitation in self-care activities, and limitation in mobility.

The analyses were conducted in Stata SE 11 (StataCorp College Station, TX). We used analytic weights to account for the complex sampling strategy and the svy commands in Stata to produce standard errors on the estimates. The subpop option in Stata was used to produce point and variance estimates for the study population that is a subset of total population of NHATS. A significance level of $\alpha = 0.05$ was used for the analyses.

Results

The study population represented approximately 33.4 million adults ages 65 or older who living in community or residential settings in the U.S. Over half of them were between 65 and 74 (54.1%), 33.6% were between 75 and 84, and 12.3% were older than age 85. Females accounted for 57.3% of the study population. The major race and ethnicity was White, non-Hispanic (80.9%), followed by Black, non-Hispanic (8.1%), Hispanic (6.2%), and others (4.9%) (**Table 1**).

Approximately two thirds of community-dwelling older adults had two or more condition clusters, 26.5% had one condition cluster, and 7.7% had none. Older adults with two or more condition clusters were different from those who had one cluster or none in many socio-demographic characteristics and functional status. Higher proportions of older adults with two or more condition clusters were age 75 or older, female, less educated, at the lowest two quartiles of income, and widowed.

Proportions of people with limitation in self-care activities, mobility, household tasks, dementia, and depressive symptoms were also higher among older adults with two or more condition clusters. Approximately 40% of older adults with two or more condition clusters had family involvement in health care activities (**Table 1**).

More than one third of older adults in U.S. experienced any treatment burden (37.6%, **Table 2**) The most prevalent treatment burden is difficulty in self-managing (25.3%), followed by difficulty experienced by family or close friends (23.5%), non-adherence to treatment regimens (22.2%) and feeling overwhelmed (12.7%). In bivariate analyses, we found that having three or more condition clusters was associated with higher odds of difficulty in self-managing health, non-adherence to treatment regimens, and feeling overwhelmed, compared to having one condition cluster (32.4% vs. 23.8%, OR=1.53, p=0.02 for self-managing health; 27.9% vs. 21.8%, OR=1.39, p=0.04 for non-adherence; 17.2% vs. 10.9% OR=1.69, p=0.03, respectively. **Table 3**). We found a dose-response association between experience of any treatment burden and the number of condition clusters- the more condition clusters an older adult had, the more likely he/she experienced treatment burden. Older adults with three or more condition clusters were statistically significantly more likely to experience with any treatment burden than those with one condition cluster (45.1% vs. 34.8%, OR=1.5, p<0.01). The number of condition clusters was not associated with difficulty experienced by

family or close friends (OR=1.20, p=0.4). However, having three or more condition clusters was not associated with higher odds of experiencing any treatment burden compared to having one condition cluster or non after accounting for age, educational attainment, depressive symptoms, limitation in self-care activities, and limitation in mobility (**Table 4**).

Discussion

Adherence to treatment regimens, required lifestyle modifications, and home monitoring activities are critical for maintaining health at the optimal level among older adults with multimorbidity; however, the workload required may be burdensome to some older adults.[47] Drawing upon data from a nationally representative survey on the elderly population in U.S., we find older adults living in community or residential settings who have three or more condition clusters are more likely to report experiences with any treatment burden compared to those who have one condition cluster when other factors, such as functional status and psychological factors are not accounted for. More specifically, older adults are more likely to report difficulty in self-managing health, non-adherence to treatment regimens, and feeling overwhelmed if they have three or more condition clusters. Our findings suggest that having coexisting conditions that are unrelated, i.e. in different clusters, may exacerbate treatment burden of older adults with multimorbidity. This could result from increased complexity of implementing multiple self-management activities and treatment regimens concurrently and/or

individuals' confusion about contradictory treatment plans for unrelated conditions.

The finding that the association between the number of condition clusters and treatment burden is not statistically significant after controlling for age, gender, marital status, educational attainment, depressive symptoms and functional status is consistent with the cumulative complexity model that implies treatment burden is driven by workload and ability imbalances.[48] Individuals who have high ability, for example, those who are higher educated and have better functional status, may be less likely to feel burden even with increased workload of demands on managing health.[48] It is important to note that individual's ability to accomplish self-management tasks may decrease as a consequence of unrelated conditions that are severe and dominate treatment plans.[32] This study demonstrates that the number of condition clusters, along with functional status and psychological factors, have impact on treatment burden perceived by older adults with multimorbidity.

This study offers novel contributions to the multimorbidity literature not only because the study population is drawn from a nationally representative population-based survey among community-dwelling older adults, but also because we examine treatment burden in relation to different multimorbidity patterns, measured as the number of condition clusters, which has yet to be studied elsewhere. Existing

literature on burden related to taking medications, attending medical appointments, lifestyle modification on diet and exercise indicates that greater burden is associated with increased number of coexisting conditions.[15,32] A few specific conditions, such as heart failure, stroke, and hypertension, are shown to increase treatment burden in bivariate analyses. Other conditions, such as vision impairment, hearing impairment, and falls, are associated with increased burden because they are linked to difficulty in understanding and implementing treatment regimens.[15] These selected conditions can be grouped into three clusters– cardiopulmonary (heart failure, stroke, hypertension), sensory-motor (hearing and visual impairment), and osteoporosis-arthritis (related to falls)- according to our method. This agrees well with our unadjusted finding that having more condition clusters is associated with higher odds of difficulty in self-managing health and non-adherence. This implies that having additional clusters adds more complexity on implementing self-management activities and adhering to treatment regimens beyond burden resulted from managing multiple conditions in the same cluster. This also supports the assertion that measuring multimorbidity in the number of condition clusters is a practical and simple tool to operationalize inter-relatedness between conditions and to assess the impact of inter-relatedness between conditions on treatment burden.[25,29]

Compared to other quantitative studies that use perceived

difficulty as measure to treatment burden, we find higher rates of treatment burden in our study.[15,32] The difference may be due to differences in the study populations as the VA population is primarily male and their results may have limited generalizability.[32] Men tend to report less treatment burden than women.[49,50] Or this may also be due to difference in measures- the other study uses task-specific measures for health care activities (e.g. one measure for obtaining medication, one for planning medication schedule, etc), whereas our study uses general measures (i.e., measures for all activities related managing health).[15] The use of general measures allows us assess treatment burden associated with the entire care experience, which has wide applicability to the multimorbidity population as required health care tasks may vary across individuals with multimorbidity.

This study has several limitations. First, the measures for treatment burden in this study are not specific to the four components of treatment burden. Assessing treatment burden by components may provide more information on guiding interventions to reduce treatment burden. For instance, individuals who report having significant time or travel burden may benefit from home health services or home delivery services for medications in order to improve self-management and treatment adherence, respectively. Due to the inter-relatedness of the components, it may however be difficult to distinguish these components. Using general measures of treatment burden, we provide a broader yet

relevant aspect of treatment burden among the multimorbidity population. Inclusion of other important factors to treatment burden, such as self-efficacy, health literacy, would be ideal. Unfortunately, such information is not available in NHATS. Lastly, this is a cross-sectional study, so the causal relationship between treatment burden and multimorbidity patterns cannot be established.

Treatment burden experienced by older adults can be comprised of individual-level characteristics (e.g. age, gender, coexisting conditions, functional status, and depressive symptoms etc) and system-level characteristics (e.g. care coordination across providers and payment design etc).[51] This study identifies a number of key drivers of treatment burden, such as the presence of multiple clusters of related conditions. As hypothesized, adding additional clusters may increase individuals' treatment burden. This is likely due to increased workload and decreased ability caused by conditions in a different cluster. However, it is worth mentioning that even with receiving same treatment regimens and self-management activities suggestions and being well informed, individuals are likely to vary in the burden they perceive. The variation can be contributed to several factors, including individuals' ability to take on workload and individuals' willingness to accept burdensome treatment.

Individuals' ability to perform workload depends upon their functional status, cognitive status, psychological factors, such as depressive symptoms, and their financial, social resources. Factors that

affect individuals' willingness to accept burdensome treatment include self-efficacy, health literacy, attitude/beliefs, and other socio-demographic characteristics. Moreover, individuals' treatment burden may change over time. As individuals adapt and routinize self-management activities, usually among individuals have managed their conditions for a longer time, individuals' experience of treatment burden may lessen. Thus it is very important for health care providers to assess individuals' perceived treatment burden over time in clinical settings. Through assessing treatment burden, providers may gather information on individuals' preferences and prioritization process, as well as identify situations where additional assistance would be beneficial to individuals and their family or close friends. Assessing treatment burden is particularly beneficial in caring for individuals with multimorbidity. There is currently little guidance on how to combine disease-specific guidelines and individuals' preferences to create treatment regimens for older adults with multimorbidity. Providers may adjust treatment regimens, if feasible, to address treatment burden and to ensure that the care plan aligns with individuals' preferences.

Conclusion

Better understanding of the burden associated with following required self-management activities and adhering to treatment regimens among older adults with multimorbidity is important. Our findings suggest that having coexisting conditions that are unrelated, i.e. in

multiple clusters, may exacerbate treatment burden of older adults with multimorbidity. Moreover, other factors such as functional status and psychological factors also affect whether or not older adults perceive managing their health as burden. In clinical settings, assessing individuals' treatment burden over time, identifying individuals who have significant treatment burden, and then modifying their treatment plans to alleviate treatment burden are important steps toward providing person-centered care.

Table 1: Socio-demographic characteristics and health-care related factors among community-dwelling older adults by number of condition clusters in U.S.

Column %	All	Number of condition clusters			p-value *
		0	1	2 & +	
Total (in millions)	33.4	2.5	8.9	22.0	
		7.7%	26.5%	65.8%	
Age in category (R1)					
Age 65-74	54.1%	68.7%	61.6%	49.4%	<0.01
Age 75-84	33.6%	22.3%	30.5%	36.1%	
Age 85+	12.3%	9.0%	7.9%	14.4%	
Female	57.3%	43.6%	49.7%	62.0%	<0.01
Male	42.7%	56.4%	50.3%	38.0%	
Race and ethnicity					
1 White, non-Hispanic	80.9%	81.7%	81.0%	80.7%	0.21
2 Black, non-Hispanic	8.1%	5.6%	7.0%	8.8%	
3 Hispanic	6.2%	4.2%	6.8%	6.2%	
4 Others	4.9%	8.5%	5.2%	4.3%	
High school diploma	78.6%	85.8%	84.7%	75.4%	<0.01
Less than high school	21.4%	14.2%	15.3%	24.6%	
Household income v3					
1 1st lowest quartile	20.2%	17.6%	16.0%	22.2%	<0.01
2 2nd quartile	23.2%	20.4%	18.3%	25.4%	
3 3rd quartile	23.4%	16.7%	23.8%	24.0%	
4 4th quartile	33.3%	45.2%	42.0%	28.4%	
Marital status					
1 Married/Living with a partner	57.3%	68.1%	61.5%	54.3%	<0.01
2 Widowed	26.0%	15.7%	20.7%	29.3%	
3 Separated/Divorced/Never married	16.8%	16.2%	17.8%	16.4%	

Column %	All	Number of condition clusters			p-value*
		0	1	2 & +	
Limitation in self-care activities	24.5%	6.2%	13.2%	31.2%	<0.01
No limitation in self-care activities	75.5%	93.8%	86.8%	68.8%	
Limitation in mobility	29.4%	8.3%	19.8%	35.8%	<0.01
No limitation in mobility	70.6%	91.7%	80.2%	64.2%	
Limitation in household tasks	34.6%	14.1%	20.6%	42.6%	<0.01
No limitation in household tasks	65.4%	85.9%	79.4%	57.4%	
No dementia	81.4%	85.4%	86.5%	78.8%	<0.01
Possible dementia	8.5%	10.4%	6.7%	9.0%	
Probable dementia	10.1%	4.2%	6.8%	12.2%	
Depressive symptoms	7.2%	2.9%	3.0%	9.4%	<0.01
No depressive symptoms	92.8%	97.1%	97.0%	90.6%	
Family involvement in health care activities	35.7%	17.4%	27.7%	41.0%	<0.01
No family involvement in health care activities	64.3%	82.6%	72.3%	59.0%	

*Unweighted n=2,041

Table 2: Treatment burden by number of condition clusters among older adults in U.S.

	Difficulty in self-managing health *			Difficulty experienced by family or close friends **			Non-adherence			Feeling overwhelmed***			Any treatment burden above		
	%	OR	p-value	%	OR	p-value	%	OR	p-value	%	OR	p-value	%	OR	p-value
All	25.3%			23.5%			22.2%			12.7%			37.6%		
Number of condition clusters															
0	**14.9%**	**0.56**	**0.03**	6.8%	0.22	0.16	18.7%	0.83	0.49	13.8%	1.31	0.51	26.9%	0.69	0.13
1	23.8%	(Ref)		25.0%	(Ref)		21.8%	(Ref)		10.9%	(Ref)		34.8%	(Ref)	
2	24.5%	1.04	0.84	21.1%	0.80	0.32	20.1%	0.90	0.51	11.3%	1.03	0.87	37.3%	1.12	0.44
3 or more	**32.4%**	**1.53**	**0.02**	28.6%	1.20	0.48	**27.9%**	**1.39**	**0.04**	**17.2%**	**1.69**	**0.03**	**45.1%**	**1.54**	**<0.01**

Bold entries are significant at p<0.05.

* Given that this question was fielded with skip patterns, the denominator included older adults who were fielded this question only (i.e., older adults who reported mostly handling health by self, handling together with family or close friends, and it varies) (n=1,578).

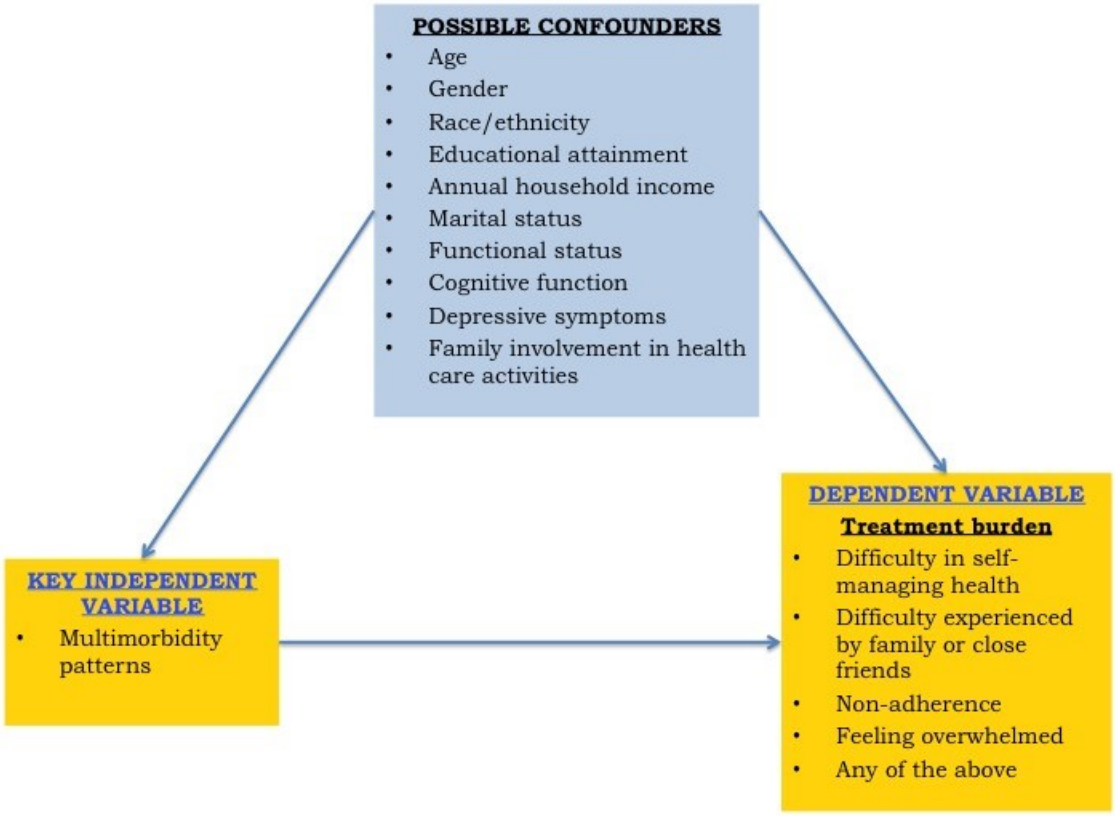
** Given that this question was fielded with skip patterns, the denominator included older adults who were fielded this question only (i.e., older adults who reported that mostly handling by family or close friends, handling together with family or close friends, and it varies) (n=723).

*** Older adults who reported "never" to the "non-adherence" question were not asked the "feeling overwhelmed" question, and these people were considered as never feeling overwhelmed (n=1,003

Table 3: Multiple regression model results

OR (p-value)	Difficulty in self-managing health (Model 1)	Difficulty experienced by family or closed friends (Model 2)	Non-adherence (Model 3)	Feeling overwhelmed (Model 4)	Any treatment burden above (Model 5)
Age 65-84	**2.40 (<0.01)**	**3.72 (<0.01)**	**2.69 (0.02)**	**2.61 (<0.01)**	**2.46 (<0.01)**
Female	0.97 (0.84)	1.10 (0.43)	1.13 (0.44)	1.01 (0.92)	1.01 (0.92)
Not married	1.67 (0.11)	**2.51 (<0.01)**	1.40 (0.47)	**1.79 (0.03)**	1.36 (0.31)
Age 65-84 x not married	**0.43 (<0.01)**	**0.36 (<0.01)**	0.54 (0.23)	**0.47 (0.01)**	**0.52 (0.04)**
No high school diploma	**1.51 (<0.01)**	1.21 (0.21)	1.30 (0.10)	**1.38 (0.01)**	**1.38 (0.02)**
Depressive symptoms	**1.629* (0.02)**	1.32 (0.22)	**2.32 (<0.01)**	**1.49 (0.02)**	**1.55 (0.02)**
Limitation in self-care activities	**2.03 (<0.01)**	**1.42 (0.04)**	1.37 (0.17)	**1.90 (<0.01)**	**1.77 (<0.01)**
Limitation in mobility	**1.64 (<0.01)**	**1.45 (0.01)**	**1.51 (<0.05)**	**1.58 (<0.01)**	**1.53 (<0.01)**
Two condition clusters	0.94 (0.72)	0.82 (0.20)	0.81 (0.20)	1.00 (0.90)	0.96 (0.81)
Three or more condition clusters	1.20 (0.32)	1.17 (0.31)	1.19 (0.41)	1.2 (0.20)	1.18 (0.35)

Figure 1: Conceptual Framework



Conclusion

Summary of Findings

This thesis examines components related to person-centered care to older adults through three different aims.

Aim 1: (1) To examine if the presence of multimorbidity is associated with higher odds of passive role preferences in medical decision-making, and (2) to identify multimorbidity patterns that are associated with higher odds of passive role preferences in medical decision-making.

Despite that the majority of older adults stated that they prefer an active or collaborative role in decision-making, older adults with multiple clusters of related conditions are more likely to state that they prefer to leave decisions up to their providers (i.e., passive role) compared to older adults with only one cluster of conditions or none. The number of condition clusters is a useful way to understand variation in individuals' role preferences in decision-making among older adults with multimorbidity in the U.S.

Aim 2: To examine (1) differences in role preferences for medical decision-making among older adults with incident possible or probable dementia compared to older adults with no dementia, and (2) whether impaired

memory, orientation, or executive function is associated with role preferences for medical decision-making.

Despite cognitive decline, the vast majority of individuals with dementia still wants to participate in medical decision-making and are capable of expressing their needs and values. Personal values and needs should be used in guiding health care decisions for individuals with dementia. However, individuals with incident possible or probable dementia are more likely to disengage from decision-making.

Aim 3: To examine the association between multimorbidity patterns and treatment burden.

Our findings suggest that having coexisting conditions that are unrelated, i.e. in multiple clusters, may exacerbate treatment burden of older adults with multimorbidity. Moreover, other factors such as functional status and psychological factors also affect whether or not older adults perceive managing their health as burden.

Policy Implications

Person-centered care is considered as the best practice of care for older adults with complex care needs, such as older adults with multimorbidity or dementia, on which standardized care is less applicable. Individuals' active engagement in health care is key to providing person-centered care. The Affordable Care Act recognizes

individuals' engagement in care as a cornerstone to health care reform. For example, accountable care organizations are required to meet quality performance standard in order to share savings – and shared decision-making questions are included in the set of quality measures.

Our results show promising findings from the policy perspective as the majority of older adults, even with multimorbidity or dementia, stated that they want to participate in health care decision-making. However, it is also important to recognize individual variation in role preferences for decision-making. Our findings suggest that older adults with multimorbidity or dementia are associated with higher odds of preferring to leave decisions up to providers. Further research on how such variation occurs is needed as their preferences may reflect their previous negative experiences with engagement in health care, which may be amendable to some extent by policy interventions.

Moreover, multimorbidity has been well-recognized as an important challenges to older adults and to the U.S. health care systems. A particular issue with multimorbidity is the variation in multimorbidity patterns. Multimorbidity patterns differ not only by the number of co-existing conditions, but also by the characteristics of conditions, and the interaction among the conditions. However, multimorbidity patterns are often less recognized beyond a simple count of conditions in research.

The choice of ideal measures of multimorbidity patterns depends on the outcomes of interest, the availability of data, and how practical it

is to utilize the measure. This thesis demonstrates that using a simple count of condition clusters to measure multimorbidity patterns is a useful mean to understand the variation in individual's role preferences and experiences with treatment burden, which are important components of individuals' engagement in care.

Appendix 1: Prevalence of multimorbidity and multimorbidity patterns in U.S.

Approximately three-quarters of older adults (78.4%) had two or more conditions,15.2% of older adults who had one condition, and 6.4% of older adults who did not have any chronic condition (**Appendix Table 1**). Among older adults with two or more conditions, 28.8% of them had two conditions, 26.3% had three conditions, 19.2% had four conditions, and 25.8% had five or more conditions. In a measurement of condition clusters, only 10.9% of older adults who had more than two conditions had one condition cluster. Over half of them had conditions that fell into two different condition clusters (49.0%), and approximately one quarter of them had conditions that fell into three clusters (27.4%). The majority of older adults with multimorbidity had diseases that fell into the cardiopulmonary cluster (93.0%) since the prevalence of hypertension was very high –67.0% among overall population and 79.3% among the multimorbidity population, followed by the arthritis-osteoporosis cluster (75.5%), the depression-dementia cluster (27.3%), the cancer cluster (24.6%), and the sensory-motor cluster (23.0%). The five most commonly occurred condition combinations among multimorbidity group were hypertension and arthritis (8.2%), followed by the combination of hypertension, arthritis, and diabetes, the combination of hypertension, arthritis, and cancer, the combination of hypertension and diabetes (less than 3% for each of these three combinations), and the combination of

hypertension and cancer (2.0%). Even combining the five most commonly occurred condition combinations together it only accounted for less than one quarter (17.6%) of the multimorbidity population – which demonstrated the broad range of condition combinations in the multimorbidity population.

Older adults who had greater number of chronic conditions tended to have greater number of clusters of related conditions (**Appendix Table 2**). Over 90% and over 95% of older adults who had three and four conditions, respectively, had conditions that fall into at least two different clusters, as compared to only 73.1% did so among those who have two conditions.

Table 1.1: Prevalence of multimorbidity, and its patterns among older adults living in community/residential settings in the U.S.

	Percentage
Multimorbidity	
0 no condition	6.4%
1 single condition	15.2%
2 two or more conditions	78.4%
By number of conditions*	
2 conditions	28.8%
3 conditions	26.3%
4 conditions	19.2%
5 or more conditions	25.8%
By number of condition clusters*	
1 condition cluster	10.9%
2 condition clusters	49.0%
3 condition clusters	27.4%
4 or more condition clusters	12.7%
By cluster*	
Cardiopulmonary	93.0%
Sensory-motor	23.0%
Depression-dementia	27.3%
Arthritis-osteoporosis	75.5%
Cancer	24.6%
By most commonly occurred condition combination*	
1. Hypertension & arthritis	8.2%
2. Hypertension, arthritis, & diabetes	2.7%
3. Hypertension, arthritis, & cancer	2.3%
4. Hypertension & diabetes	2.4%
5. Hypertension & cancer	2.0%

Unweighted n=2,017

Table 1.2: Cross-tabulation between number of condition clusters and number of conditions among older adults with multimorbidity living in community/residential settings in the U.S.

Row %	1 cluster	2 clusters	3 clusters	4 or more clusters
2 conditions	26.9%	73.1%	0.0%	0.0%
3 conditions	7.5%	57.9%	34.5%	0.0%
4 conditions	3.8%	42.3%	41.6%	12.3%
5 or more conditions	1.7%	17.9%	40.2%	40.2%

Unweighted n=1,654

Bibliography

Chapter 1

1. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T. Through the patientLs eyes. . 1993.

2. Bloom BS. Crossing the quality chasm: A new health system for the 21st century. *JAMA: The Journal of the American Medical Association*. 2002;287(5):646-647.

3. Kaplan SH, Greenfield S, Ware Jr JE. Assessing the effects of physician-patient interactions on the outcomes of chronic disease. *Med Care*. 1989;27(3):S110-S127.

4. Dwamena F, Holmes-Rovner M, Gaulden CM, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database Syst Rev*. 2012;12.

5. O'Hair D, Villagran MM, Wittenberg E, et al. Cancer survivorship and agency model: Implications for patient choice, decision making, and influence. *Health Commun*. 2003;15(2):193-202.

6. Starfield B. Is patient-centered care the same as person-focused care? *Perm J*. 2011;15(2):63-69.

7. Mounier E. Personalism, trans. *Philip Mairet (Notre Dame: University of Notre Dame Press, 1952), xxvii*. 1952.

8. Bayliss EA, Bonds DE, Boyd CM, et al. Understanding the context of health for persons with multiple chronic conditions: Moving from what is the matter to what matters. *Ann Fam Med*. 2014;12(3):260-269.

9. Reuben DB, Tinetti ME. Goal-oriented patient care—an alternative health outcomes paradigm. *N Engl J Med*. 2012;366(9):777-779.

10. Kitwood T. Dementia reconsidered: The person comes first. *Adult Lives: A Life Course Perspective*. 2011:89.

11. Kitwood T. On being a person. *Dementia reconsidered: The person comes first*. 1997:7-19.

12. Cebul RD, Rebitzer JB, Taylor LJ, Votruba M. *Organizational fragmentation and care quality in the US health care system*. 2008.

13. Boyd C, Darer J, Boult C, Fried L, Boult L, Wu A. Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases implications for pay for performance. *Journal of American Medical Association*. 2005;294(6):716-724.

14. Stange KC. The problem of fragmentation and the need for integrative solutions. *Ann Fam Med*. 2009;7(2):100-103.

15. Barnett K, Mercer SW, Norbury M, Watt G, Wyke S, Guthrie B. Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. *The Lancet*. 2012;380(9836):37-43.

16. Hubbard G, Downs M, Tester S. Including the perspectives of older people in institutional care during the consent process. *The perspectives of people with dementia.Research methods and motivations*. 2002:63-82.

17. Dewing J. From ritual to relationship A person-centred approach to consent in qualitative research with older people who have a dementia. *Dementia*. 2002;1(2):157-171.

18. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean?(or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681-692.

19. May C, Montori VM, Mair FS. We need minimally disruptive medicine. *BMJ*. 2009;339:b2803.

20. Montori VM, Brito JP, Murad MH. The optimal practice of evidence-based medicine: Incorporating patient preferences in practice guidelines. *JAMA*. 2013;310(23):2503-2504.

21. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. *Health Serv Res*. 2004;39(4p1):1005-1026.

22. Menne HL, Whitlatch CJ. Decision-making involvement of individuals with dementia. *Gerontologist*. 2007;47(6):810-819.

Chapter 2

1. van den Akker M, Buntinx F, Knottnerus JA. Comorbidity or multimorbidity: What's in a name? A review of literature. *Eur J Gen Prac*. 1996;2(2):65-70.

2. Anderson G, Horvath J. Chronic conditions: Making the case for ongoing care. . 2002.

3. Centers for Disease Control (CDC). The state of aging and health in america 2013. *Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services*. 2013.

4. Kronick RG, Bella M, Gilmer TP, Somers SA. The faces of medicaid II: Recognizing the care needs of people with multiple chronic conditions. . 2007.

5. Salive ME. Multimorbidity in older adults. *Epidemiol Rev*. 2013;35:75-83.

6. Anderson G, Horvath J. The growing burden of chronic disease in America. *Public Health Rep*. 2004;119(3):263-270.

7. Incalzi RA, Capparella O, Gemma A, et al. The interaction between age and comorbidity contributes to predicting the mortality of geriatric patients in the acute-care hospital. *J Intern Med*. 1997;242(4):291-298.

8. Librero J, Peiró S, Ordiñana R. Chronic comorbidity and outcomes of hospital care: Length of stay, mortality, and readmission at 30 and 365 days. *J Clin Epidemiol*. 1999;52(3):171-179.

9. Kadam U, Croft P. Clinical multimorbidity and physical function in older adults: A record and health status linkage study in general practice. *Fam Pract*. 2007;24(5):412-419.

10. Marengoni A, Von Strauss E, Rizzuto D, Winblad B, Fratiglioni L. The impact of chronic multimorbidity and disability on functional decline and survival in elderly persons. A community-based, longitudinal study. *J Intern Med*. 2009;265(2):288-295.

11. Fortin M, Lapointe L, Hudon C, Vanasse A, Ntetu A, Maltais D. Multimorbidity and quality of life in primary care: A systematic review. *Health Qual Life Outcomes*. 2004;2(1):51.

12. Fortin M, Bravo G, Hudon C, et al. Relationship between multimorbidity and health-related quality of life of patients in primary care. *Qual Life Res*. 2006;15(1):83-91.

13. Boyd CM, Fortin M. Future of multimorbidity research: How should understanding of multimorbidity inform health system design? *Public Health Rev*. 2010;32(2):451-474.

14. Wolff J, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Arch Intern Med*. 2002;162(20):2269-2276.

15. Glynn LG, Valderas JM, Healy P, et al. The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. *Fam Pract*. 2011;28(5):516-523.

16. Fortin M, Soubhi H, Hudon C, Bayliss EA, van den Akker M. Multimorbidity's many challenges. *BMJ*. 2007;334(7602):1016-1017.

17. Boyd C, McNabney M, Brandt N, et al. Guiding principles for the care of older adults with multimorbidity: An approach for clinicians: American geriatrics society expert panel on the care of older adults with multimorbidity. *J Am Geriatr Soc*. 2012;60(10):E1-E25.

18. Muth C, van den Akker M, Blom JW, et al. The ariadne principles: How to handle multimorbidity in primary care consultations. *BMC Med*. 2014;12(1):223.

19. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition—multimorbidity. *JAMA*. 2012;307(23):2493-2494.

20. Zulman DM, Asch SM, Martins SB, Kerr EA, Hoffman BB, Goldstein MK. Quality of care for patients with multiple chronic conditions: The role of comorbidity interrelatedness. *J Gen Intern Med*. 2014;29(3):529-537.

21. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean?(or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681-692.

22. Joosten EA, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CP, de Jong CA. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. *Psychother Psychosom*. 2008;77(4):219-226.

23. O'Connor AM, Bennett CL, Stacey D, et al. Decision aids for people facing health treatment or screening decisions. *The Cochrane Library*. 2009.

24. Arterburn D, Wellman R, Westbrook E, et al. Introducing decision aids at group health was linked to sharply lower hip and knee surgery rates and costs. *Health Aff (Millwood)*. 2012;31(9):2094-2104.

25. Protection P, Act AC. Patient protection and affordable care act. *Public Law*. 2010:111-148.

26. Oshima Lee E, Emanuel EJ. Shared decision making to improve care and reduce costs. *N Engl J Med*. 2013;368(1):6-8.

27. Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. *N Engl J Med*. 2012;366(9):780-781.

28. Harris M, Dennis S, Pillay M. Multimorbidity: Negotiating priorities and making progress. *Aust Fam Physician*. 2013;42(12):850-854.

29. Boult C, Wieland GD. Comprehensive primary care for older patients with multiple chronic conditions: “Nobody rushes you through”. *JAMA*. 2010;304(17):1936-1943.

30. Arora NK, McHorney CA. Patient preferences for medical decision making: Who really wants to participate? *Med Care*. 2000;38(3):335-341.

31. Ekdahl AW, Andersson L, Wirehn AB, Friedrichsen M. Are elderly people with co-morbidities involved adequately in medical decision making when hospitalised? A cross-sectional survey. *BMC Geriatr*. 2011;11:46.

32. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *J Gen Intern Med*. 2005;20(6):531-535.

33. Zikmund-Fisher BJ, Couper MP, Singer E, et al. The DECISIONS study: A nationwide survey of united states adults regarding 9 common medical decisions. *Med Decis Making*. 2010;30(5 Suppl):20S-34S.

34. Wolff JL, Boyd CM. A look at person-centered and family-centered care among older adults: Results from a national survey. *J Gen Intern Med*. 2015;30(10):1497-1504.

35. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. *Patient Educ Couns*. 2006;60(2):102-114.

36. Benbassat J, Pilpel D, Tidhar M. Patients' preferences for participation in clinical decision making: A review of published surveys. *Behav Med*. 1998;24(2):81-88.

37. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *J Gen Intern Med*. 2005;20(6):531-535.

38. Murray E, Pollack L, White M, Lo B. Clinical decision-making: Patients' preferences and experiences. *Patient Educ Couns*. 2007;65(2):189-196.

39. Kasper J, Freedman V. National health and aging trends study user guide: Rounds 1 & 2, final release. . 2014.

40. O'Donnell M, Hunskaar S. Preferences for involvement in treatment decision-making generally and in hormone replacement and urinary

incontinence treatment decision-making specifically. *Patient Educ Couns*. 2007;68(3):243-251.

41. Florin J, Ehrenberg A, Ehnfors M. Clinical decision-making: Predictors of patient participation in nursing care. *J Clin Nurs*. 2008;17(21):2935-2944.

42. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med*. 1988;27(11):1139-1145.

43. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy. *J Gen Intern Med*. 1989;4(1):23-30.

44. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA*. 1997;277(18):1485-1492.

45. Azarpazhooh A, Dao T, Ungar WJ, et al. Clinical decision making for a tooth with apical periodontitis: The patients' preferred level of participation. *J Endod*. 2014;40(6):784-789.

46. Britt HC, Harrison CM, Miller GC, Knox SA. Prevalence and patterns of multimorbidity in Australia. *Med J Aust*. 2008;189(2):72-77.

47. Fortin M, Bravo G, Hudon C, Vanasse A, Lapointe L. Prevalence of multimorbidity among adults seen in family practice. *Ann Fam Med*. 2005;3(3):223-228.

48. van den Akker M, Buntinx F, Metsemakers JF, Roos S, Knottnerus JA. Multimorbidity in general practice: Prevalence, incidence, and

determinants of co-occurring chronic and recurrent diseases. *J Clin Epidemiol*. 1998;51(5):367-375.

49. Schäfer I, Hansen H, Schön G, et al. The influence of age, gender and socio-economic status on multimorbidity patterns in primary care. first results from the multicare cohort study. *BMC Health Serv Res*. 2012;12(1):89.

50. Minas M, Koukosias N, Zintzaras E, Kostikas K, Gourgoulianis KI. Prevalence of chronic diseases and morbidity in primary health care in central Greece: An epidemiological study. *BMC Health Serv Res*. 2010;10:252.

51. Gold R, Michael YL, Whitlock EP, et al. Race/ethnicity, socioeconomic status, and lifetime morbidity burden in the women's health initiative: A cross-sectional analysis. *J Womens Health*. 2006;15(10):1161-1173.

52. Quinones AR, Liang J, Bennett JM, Xu X, Ye W. How does the trajectory of multimorbidity vary across Black, White, and Mexican Americans in middle and old age? *J Gerontol B Psychol Sci Soc Sci*. 2011;66(6):739-749.

53. Verbrugge LM, Lepkowski JM, Imanaka Y. Comorbidity and its impact on disability. *Milbank Q*. 1989:450-484.

54. Laidsaar-Powell R, Butow P, Bu S, et al. Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Educ Couns*. 2013;91(1):3-13.

55. Roter DL, Stewart M, Putnam SM, Lipkin M, Stiles W, Inui TS. Communication patterns of primary care physicians. *JAMA*. 1997;277(4):350-356.

56. Kasper JD, Freedman VA, Spillman B. Classification of persons by dementia status in the national health and aging trends study. technical paper #5. . 2013.

57. Wallhagen MI, Strawbridge WJ, Shema SJ, Kurata J, Kaplan GA. Comparative impact of hearing and vision impairment on subsequent functioning. *J Am Geriatr Soc*. 2001;49(8):1086-1092.

58. Löwe B, Wahl I, Rose M, et al. A 4-item measure of depression and anxiety: Validation and standardization of the patient health questionnaire-4 (PHQ-4) in the general population. *J Affect Disord*. 2010;122(1):86-95.

59. Morris JC. Revised criteria for mild cognitive impairment may compromise the diagnosis of Alzheimer disease dementia. *Arch Neurol*. 2012;69(6):700-708.

60. Seshadri S, Beiser A, Au R, et al. Operationalizing diagnostic criteria for Alzheimer's disease and other age-related cognitive impairment—Part 2. *Alzheimers Dement*. 2011;7(1):35-52.

61. John R, Kerby DS, Hennessy CH. Patterns and impact of comorbidity and multimorbidity among community-resident american indian elders. *Gerontologist*. 2003;43(5):649-660.

62. Freedman VA, Spillman BC. Disability and care needs among older Americans. *Milbank Q*. 2014;92(3):509-541.

63. Lee S, Nguyen HA, Tsui J. Interview language: A proxy measure for acculturation among Asian Americans in a population-based survey. *J Immigr Minor Health*. 2011;13(2):244-252.

64. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA*. 1963;185(12):914-919.

65. Lawton M, Brody E. Assessment of older people: Self-maintaining and instrumental activities of daily living. *Nurs Res*. 1969;9(3 Part 1):179-186.

66. Allen SM, Piette ER, Mor V. The adverse consequences of unmet need among older persons living in the community: Dual-eligible versus Medicare-only beneficiaries. *J Gerontol B Psychol Sci Soc Sci*. 2014;69 Suppl 1:S51-8.

67. Freedman VA, Kasper JD, Cornman JC, et al. Validation of new measures of disability and functioning in the national health and aging trends study. *J Gerontol A Biol Sci Med Sci*. 2011;66(9):1013-1021.

68. Wolff JL, Roter DL. Family presence in routine medical visits: A meta-analytical review. *Soc Sci Med*. 2011;72(6):823-831.

69. Degner LF, Sloan JA. Decision making during serious illness: What role do patients really want to play? *J Clin Epidemiol*. 1992;45(9):941-950.

70. Stiggelbout AM, Kiebert GM. A role for the sick role. patient preferences regarding information and participation in clinical decision-making. *CMAJ*. 1997;157(4):383-389.

71. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BMJ*. 2000;321(7265):867-871.

72. Mavaddat N, Valderas JM, van der Linde R, Khaw KT, Kinmonth AL. Association of self-rated health with multimorbidity, chronic disease and psychosocial factors in a large middle-aged and older cohort from general practice: A cross-sectional study. *BMC Fam Pract*. 2014;15(1):185.

73. Watt S. Clinical decision-making in the context of chronic illness. *Health Expect*. 2000;3(1):6-16.

74. Fung CH, Setodji CM, Kung F, et al. The relationship between multimorbidity and patients' ratings of communication. *J Gen Intern Med*. 2008;23(6):788-793.

75. Kenny P, Quine S, Shiell A, Cameron S. Participation in treatment decision-making by women with early stage breast cancer. *Health Expect*. 1999;2(3):159-168.

76. Thorne SE, Paterson BL. Health care professional support for self-care management in chronic illness: Insights from diabetes research. *Patient Educ Couns*. 2001;42(1):81-90.

77. Piette JD, Kerr EA. The impact of comorbid chronic conditions on diabetes care. *Diabetes Care*. 2006;29(3):725-731.

78. Boyd C, Darer J, Boult C, Fried L, Boult L, Wu A. Clinical practice guidelines and quality of care for older patients with multiple comorbid diseases implications for pay for performance. *JAMA*. 2005;294(6):716-724.

79. Parekh AK, Barton MB. The challenge of multiple comorbidity for the US health care system. *JAMA*. 2010;303(13):1303-1304.

80. Agency for Healthcare Research and Quality. Section 3: Selecting and targeting populations for a care management program. Rockville, MD. http://www.ahrq.gov/professionals/systems/long-term-care/resources/hcbs/medicaidmgmt/medicaidmgmt3.htm. Updated October 2014. Accessed October/01, 2015.

81. Deber RB, Kraetschmer N, Urowitz S, Sharpe N. Do people want to be autonomous patients? preferred roles in treatment decision-making in several patient populations. *Health Expect*. 2007;10(3):248-258.

82. Hibbard JH, Stockard J, Mahoney ER, Tusler M. Development of the patient activation measure (PAM): Conceptualizing and measuring activation in patients and consumers. Health Serv Res. 2004;39(4p1):1005-1026.

83. Beaver K, Luker KA, Owens RG, Leinster SJ, Degner LF, Sloan JA. Treatment decision making in women newly diagnosed with breast cancer. *Cancer Nur*s. 1996;19(1):8-19.

84. Catalan J, Brener N, Andrews H, et al. Whose health is it? views about decision-making and information-seeking from people with HIV infection and their professional carers. *AIDS Car*e. 1994;6(3):349-356.
85. Butow PN, Maclean M, Dunn SM, Tattersall MH, Boyer MJ. The dynamics of change: Cancer patients' preferences for information, involvement and support. *Ann Onco*l. 1997;8(9):857-863.
86. Mansell D, Poses RM, Kazis L, Duefield CA. Clinical factors that influence patients' desire for participation in decisions about illness. *Arch Intern Me*d. 2000;160(19):2991-2996.
87. Marengoni A, Rizzuto D, Wang H, Winblad B, Fratiglioni L. Patterns of chronic multimorbidity in the elderly population. *J Am Geriatr So*c. 2009;57(2):225-230.
88. Kirchberger I, Meisinger C, Heier M, et al. Patterns of multimorbidity in the aged population. results from the KORA-age study. *PloS on*e. 2012;7(1):e30556.
89. McKinstry B. Do patients wish to be involved in decision making in the consultation? A cross sectional survey with video vignettes. *BM*J. 2000;321(7265):867-871.
90. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologis*t. 2005;45(3):381-388.
91. Horton-Deutsch S, Twigg P, Evans R. Health care decision-making of persons with dementia. *Dementi*a. 2007;6(1):105-120.

92. Hamann J, Bronner K, Margull J, et al. Patient participation in medical and social decisions in Alzheimer's disease. *J Am Geriatr Soc*. 2011;59(11):2045-2052.

93. Fetherstonhaugh D, Tarzia L, Nay R. Being central to decision making means I am still here!: The essence of decision making for people with dementia. *J Aging Stud*. 2013;27(2):143-150.

94. Smebye KL, Kirkevold M, Engedal K. How do persons with dementia participate in decision making related to health and daily care? a multi-case study. *BMC Health Serv Res*. 2012;12:241.

95. Kriegsman DM, Penninx BW, Van Eijk, Jacques Th M, Boeke AJP, Deeg DJ. Self-reports and general practitioner information on the presence of chronic diseases in community dwelling elderly: A study on the accuracy of patients' self-reports and on determinants of inaccuracy. *J Clin Epidemiol*. 1996;49(12):1407-1417.

96. Pipe T, Conner K, Dansky K, Schraeder C, Caruso E. Perceived involvement in decision-making as a predictor of decision satisfaction in older adults. *SOJNR*. 2005;6(4):1-13.

97. Hack TF, Degner LF, Dyck DG. Relationship between preferences for decisional control and illness information among women with breast cancer: A quantitative and qualitative analysis. *Soc Sci Med*. 1994;39(2):279-289.

98. O'Dell KJ, Volk RJ, Cass AR, Spann SJ. Screening for prostate cancer with the prostate-specific antigen test: Are patients making informed decisions? *J Fam Prac*t. 1999;48(9):682-688.

99. Strull WM, Lo B, Charles G. Do patients want to participate in medical decision making? *JAM*A. 1984;252(21):2990-2994.

100. Sutherland HJ, Llewellyn-Thomas HA, Lockwood GA, Tritchler DL, Till JE. Cancer patients: Their desire for information and participation in treatment decisions. *J R Soc Me*d. 1989;82(5):260-263.

101. Chewning B, Bylund CL, Shah B, Arora NK, Gueguen JA, Makoul G. Patient preferences for shared decisions: A systematic review. *Patient* Educ Couns. 2012;86(1):9-18.

Chapter 3

1. Hebert LE, Weuve J, Scherr PA, Evans DA. Alzheimer disease in the United States (2010-2050) estimated using the 2010 census. *Neurology*. 2013;80(19):1778-1783.

2. McKhann G, Drachman D, Folstein M, Katzman R, Price D, Stadlan EM. Clinical diagnosis of Alzheimer's disease: Report of the NINCDS-ADRDA work group under the auspices of department of health and human services task force on Alzheimer's disease. *Neurology*. 1984;34(7):939-944.

3. Plassman BL, Langa KM, Fisher GG, et al. Prevalence of dementia in the United States: The aging, demographics, and memory study. *Neuroepidemiology*. 2007;29(1-2):125-132.

4. Vincent GK, Velkoff VA. The next four decades: The older population in the United States: 2010 to 2050. US Department of Commerce, Economics and Statistics Administration, US Census Bureau; 2010.

5. Husaini BA, Sherkat DE, Moonis M, Levine R, Holzer C, Cain VA. Racial differences in the diagnosis of dementia and in its effects on the use and costs of health care services. *Psychiatric Services*. 2003;54(1):92-96.

6. Tilly J, Wiener JM, Gould E, O'Keefe J. Making the long-term services and supports system work for people with dementia and their caregivers. *Issue brief prepared by the ADSSP National Resource Center for the US*

Administration on Aging.www.adrc-tae.acl.gov/tiki-download_file.php. 2011.

7. Kasper JD, Freedman VA, Spillman BC, Wolff JL. The disproportionate impact of dementia on family and unpaid caregiving to older adults. *Health Aff (Millwood)*. 2015;34(10):1642-1649.

8. Hurd MD, Martorell P, Delavande A, Mullen KJ, Langa KM. Monetary costs of dementia in the United States. *N Engl J Med*. 2013;368(14):1326-1334.

9. Kitwood T. On being a person. *Dementia reconsidered: The person comes first*. 1997:7-19.

10. Edvardsson D, Fetherstonhaugh D, Nay R. Promoting a continuation of self and normality: Person - centred care as described by people with dementia, their family members and aged care staff. *J Clin Nurs*. 2010;19(17 - 18):2611-2618.

11. Brooker D. What is person-centred care in dementia? *Rev Clin Gerontol*. 2003;13(03):215-222.

12. Brooker D. *Person-centred dementia care: Making services better.* Jessica Kingsley Publishers; 2007.

13. Chenoweth L, King MT, Jeon Y, et al. Caring for aged dementia care resident study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *Lancet Neurol*. 2009;8(4):317-325.

14. Sudore RL, Fried TR. Redefining the “planning” in advance care planning: Preparing for end-of-life decision making. *Ann Intern Med*. 2010;153(4):256-261.

15. Menne HL, Whitlatch CJ. Decision-making involvement of individuals with dementia. *Gerontologist*. 2007;47(6):810-819.

16. Train G, Nurock S, Manela M, Kitchen G, Livingston G. A qualitative study of the experiences of long-term care for residents with dementia, their relatives and staff. *Aging Ment Health*. 2005;9(2):119-128.

17. Whitlatch CJ, Piiparinen R, Feinberg LF. How well do family caregivers know their relatives' care values and preferences? *Dementia*. 2009;8(2):223-243.

18. Karel MJ, Moye J, Bank A, Azar AR. Three methods of assessing values for advance care planning: Comparing persons with and without dementia. *J Aging Health*. 2007;19(1):123-151.

19. von Kutzleben M, Schmid W, Halek M, Holle B, Bartholomeyczik S. Community-dwelling persons with dementia: What do they need? what do they demand? what do they do? A systematic review on the subjective experiences of persons with dementia. *Aging Ment Health*. 2012;16(3):378-390.

20. Desai AK, Desai FG, McFadden S, Grossberg G. Experiences and perspectives of persons with dementia. In: *Dementia care.* Springer; 2016:151-166.

21. McKhann GM, Knopman DS, Chertkow H, et al. The diagnosis of dementia due to Alzheimer's disease: Recommendations from the national institute on aging-Alzheimer's association workgroups on diagnostic guidelines for Alzheimer's disease. *Alzheimers Dement*. 2011;7(3):263-269.

22. Bradford A, Kunik ME, Schulz P, Williams SP, Singh H. Missed and delayed diagnosis of dementia in primary care: Prevalence and contributing factors. *Alzheimer Dis Assoc Disord*. 2009;23(4):306-314.

23. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? *Gerontologist*. 2005;45(3):381-388.

24. Karel MJ, Gurrera RJ, Hicken B, Moye J. Reasoning in the capacity to make medical decisions: The consideration of values. *J Clin Ethics*. 2010;21(1):58-71.

25. Morris JC. Revised criteria for mild cognitive impairment may compromise the diagnosis of Alzheimer disease dementia. *Arch Neurol*. 2012;69(6):700-708.

26. Seshadri S, Beiser A, Au R, et al. Operationalizing diagnostic criteria for Alzheimer's disease and other age-related cognitive impairment—Part 2. *Alzheimers Dement*. 2011;7(1):35-52.

27. Morris JC, Storandt M, Miller JP, et al. Mild cognitive impairment represents early-stage Alzheimer disease. *Arch Neurol*. 2001;58(3):397-405.

28. Say R, Murtagh M, Thomson R. Patients' preference for involvement in medical decision making: A narrative review. *Patient Educ Couns*. 2006;60(2):102-114.

29. O'Donnell M, Hunskaar S. Preferences for involvement in treatment decision-making generally and in hormone replacement and urinary incontinence treatment decision-making specifically. *Patient Educ Couns*. 2007;68(3):243-251.

30. Florin J, Ehrenberg A, Ehnfors M. Clinical decision - making: Predictors of patient participation in nursing care. *J Clin Nurs*. 2008;17(21):2935-2944.

31. Arora NK, McHorney CA. Patient preferences for medical decision making: Who really wants to participate? *Med Care*. 2000;38(3):335-341.

32. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *J Gen Intern Med*. 2005;20(6):531-535.

33. Blanchard CG, Labrecque MS, Ruckdeschel JC, Blanchard EB. Information and decision-making preferences of hospitalized adult cancer patients. *Soc Sci Med*. 1988;27(11):1139-1145.

34. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy. *J Gen Intern Med*. 1989;4(1):23-30.

35. Degner LF, Kristjanson LJ, Bowman D, et al. Information needs and decisional preferences in women with breast cancer. *JAMA*. 1997;277(18):1485-1492.

36. Azarpazhooh A, Dao T, Ungar WJ, et al. Clinical decision making for a tooth with apical periodontitis: The patients' preferred level of participation. *J Endod*. 2014;40(6):784-789.

37. Katzman R. Education and the prevalence of dementia and Alzheimer's disease. *Neurology*. 1993;43(1):13-20.

38. Fratiglioni L, Grut M, Forsell Y, et al. Prevalence of Alzheimer's disease and other dementias in an elderly urban population: Relationship with age, sex, and education. *Neurology*. 1991;41(12):1886-1892.

39. Hofman A, Rocca WA, Brayne C, et al. The prevalence of dementia in europe: A collaborative study of 1980-1990 findings. eurodem prevalence research group. *Int J Epidemiol*. 1991;20(3):736-748.

40. Yaffe K, Fox P, Newcomer R, et al. Patient and caregiver characteristics and nursing home placement in patients with dementia. *JAMA*. 2002;287(16):2090-2097.

41. Helmer C, Damon D, Letenneur L, et al. Marital status and risk of Alzheimer's disease: A french population-based cohort study. *Neurology*. 1999;53(9):1953-1958.

42. Ruitenberg A, Ott A, van Swieten JC, Hofman A, Breteler MM. Incidence of dementia: Does gender make a difference? *Neurobiol Aging*. 2001;22(4):575-580.

43. Levinson W, Kao A, Kuby A, Thisted RA. Not all patients want to participate in decision making. *J Gen Intern Med*. 2005;20(6):531-535.

44. Murray E, Pollack L, White M, Lo B. Clinical decision-making: Patients' preferences and experiences. *Patient Educ Couns*. 2007;65(2):189-196.

45. Zikmund-Fisher BJ, Couper MP, Singer E, et al. The DECISIONS study: A nationwide survey of United States adults regarding 9 common medical decisions. *Med Decis Making*. 2010;30(5 Suppl):20S-34S.

46. Laidsaar-Powell R, Butow P, Bu S, et al. Physician–patient–companion communication and decision-making: A systematic review of triadic medical consultations. *Patient Educ Couns*. 2013;91(1):3-13.

47. Wolff JL, Boyd CM. A look at person-centered and family-centered care among older adults: Results from a national survey. *J Gen Intern Med*. 2015;30(10):1497-1504.

48. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: What does it mean?(or it takes at least two to tango). *Soc Sci Med*. 1997;44(5):681-692.

49. Roter DL, Stewart M, Putnam SM, Lipkin M, Stiles W, Inui TS. Communication patterns of primary care physicians. *JAMA*. 1997;277(4):350-356.

50. Kasper JD, Freedman VA, Spillman B. Classification of persons by dementia status in the national health and aging trends study. technical paper #5. . 2013.

51. Freedman VA, Spillman BC. Disability and care needs among older americans. *Milbank Q*. 2014;92(3):509-541.

52. Lee S, Nguyen HA, Tsui J. Interview language: A proxy measure for acculturation among Asian Americans in a population-based survey. *J Immigr Minor Health*. 2011;13(2):244-252.

53. Wallhagen MI, Strawbridge WJ, Shema SJ, Kurata J, Kaplan GA. Comparative impact of hearing and vision impairment on subsequent functioning. *J Am Geriatr Soc*. 2001;49(8):1086-1092.

54. Löwe B, Wahl I, Rose M, et al. A 4-item measure of depression and anxiety: Validation and standardization of the patient health questionnaire-4 (PHQ-4) in the general population. *J Affect Disord*. 2010;122(1):86-95.

55. John R, Kerby DS, Hennessy CH. Patterns and impact of comorbidity and multimorbidity among community-resident American Indian elders. *Gerontologist*. 2003;43(5):649-660.

56. Hirschman KB, Xie SX, Feudtner C, Karlawish JH. How does an Alzheimer's disease patient's role in medical decision making change over time? *J Geriatr Psychiatry Neurol*. 2004;17(2):55-60.

57. Clare L, Roth I, Pratt R. Perceptions of change over time in early-stage Alzheimer's disease implications for understanding awareness and coping style. *Dementia*. 2005;4(4):487-520.

58. Hamann J, Bronner K, Margull J, et al. Patient participation in medical and social decisions in Alzheimer's disease. *J Am Geriatr Soc*. 2011;59(11):2045-2052.

59. Pappas BA, Sunderland T, Weingartner HM, Vitiello B, Martinson H, Putnam K. Alzheimer's disease and feeling-of-knowing for knowledge and episodic memory. *J Gerontol*. 1992;47(3):P159-64.

60. Griffith HR, Dymek MP, Atchison P, Harrell L, Marson DC. Medical decision-making in neurodegenerative disease: Mild AD and PD with cognitive impairment. *Neurology*. 2005;65(3):483-485.

61. Marson DC, Chatterjee A, Ingram KK, Harrell LE. Toward a neurologic model of competency: Cognitive predictors of capacity to consent in Alzheimer's disease using three different legal standards. *Neurology*. 1996;46(3):666-672.

62. Schindler BA, Ramchandani D, Matthews MK. Competency and the frontal lobe: The impact of executive dysfunction on decisional capacity. *Psychosomatics*. 1995;36(4):400-404.

63. Seigerschmidt E, Mösch E, Siemen M, Förstl H, Bickel H. The clock drawing test and questionable dementia: Reliability and validity. *Int J Geriatr Psychiatry*. 2002;17(11):1048-1054.

64. Warner J, Milne A, Peet J. My name is not dementia. . 2010.

Chapter 4

1. Anderson G, Horvath J. The growing burden of chronic disease in America. *Public Health Rep*. 2004;119(3):263-270.

2. Salive ME. Multimorbidity in older adults. *Epidemiol Rev*. 2013;35:75-83.

3. US Department of Health and Human Services. Multiple chronic conditions—a strategic framework: Optimum health and quality of life for individuals with multiple chronic conditions. *Washington, DC: US Department of Health and Human Services*. 2010.

4. Incalzi RA, Capparella O, Gemma A, et al. The interaction between age and comorbidity contributes to predicting the mortality of geriatric patients in the acute - care hospital. *J Intern Med*. 1997;242(4):291-298.

5. Librero J, Peiró S, Ordiñana R. Chronic comorbidity and outcomes of hospital care: Length of stay, mortality, and readmission at 30 and 365 days. *J Clin Epidemiol*. 1999;52(3):171-179.

6. Kadam U, Croft P. Clinical multimorbidity and physical function in older adults: A record and health status linkage study in general practice. *Fam Pract*. 2007;24(5):412-419.

7. Marengoni A, Von Strauss E, Rizzuto D, Winblad B, Fratiglioni L. The impact of chronic multimorbidity and disability on functional decline and survival in elderly persons. A community - based, longitudinal study. *J Intern Med*. 2009;265(2):288-295.

8. Fortin M, Lapointe L, Hudon C, Vanasse A, Ntetu A, Maltais D. Multimorbidity and quality of life in primary care: A systematic review. *Health Qual Life Outcomes*. 2004;2(1):51.

9. Fortin M, Bravo G, Hudon C, et al. Relationship between multimorbidity and health-related quality of life of patients in primary care. *Qual Life Res*. 2006;15(1):83-91.

10. Boyd CM, Fortin M. Future of multimorbidity research: How should understanding of multimorbidity inform health system design? *Public Health Rev*. 2010;32(2):451-474.

11. Wolff J, Starfield B, Anderson G. Prevalence, expenditures, and complications of multiple chronic conditions in the elderly. *Arch Intern Med*. 2002;162(20):2269-2276.

12. Glynn LG, Valderas JM, Healy P, et al. The prevalence of multimorbidity in primary care and its effect on health care utilization and cost. *Fam Pract*. 2011;28(5):516-523.

13. Tinetti ME, Fried TR, Boyd CM. Designing health care for the most common chronic condition—multimorbidity. *JAMA*. 2012;307(23):2493-2494.

14. Eton DT, de Oliveira DR, Egginton JS, et al. Building a measurement framework of burden of treatment in complex patients with chronic conditions: A qualitative study. *Patient Relat Outcome Meas*. 2012;3:39.

15. Boyd CM, Wolff JL, Giovannetti E, et al. Healthcare task difficulty among older adults with multimorbidity. *Med Care*. 2014;52 Suppl 3:S118-25.

16. Haynes RB, McDonald HP, Garg AX. Helping patients follow prescribed treatment: Clinical applications. *JAMA*. 2002;288(22):2880-2883.

17. Ho PM, Rumsfeld JS, Masoudi FA, et al. Effect of medication nonadherence on hospitalization and mortality among patients with diabetes mellitus. *Arch Intern Med*. 2006;166(17):1836-1841.

18. Vijan S, Hayward RA, Ronis DL, Hofer TP. Brief report: The burden of diabetes therapy. *J Gen Intern Med*. 2005;20(5):479-482.

19. Eton DT, Elraiyah TA, Yost KJ, et al. A systematic review of patient-reported measures of burden of treatment in three chronic diseases. *Patient Relat Outcome Meas*. 2013;4:7.

20. Tran V, Harrington M, Montori VM, Barnes C, Wicks P, Ravaud P. Adaptation and validation of the treatment burden questionnaire (TBQ) in english using an internet platform. *BMC Med*. 2014;12(1):109.

21. Sav A, Kendall E, McMillan SS, et al. 'You say treatment, I say hard work': Treatment burden among people with chronic illness and their carers in australia. *Health Soc Care Community*. 2013;21(6):665-674.

22. Eton DT, Ridgeway JL, Egginton JS, et al. Finalizing a measurement framework for the burden of treatment in complex patients with chronic conditions. *Patient Relat Outcome Meas*. 2015;6:117.

23. de Groot V, Beckerman H, Lankhorst GJ, Bouter LM. How to measure comorbidity: A critical review of available methods. *J Clin Epidemiol*. 2003;56(3):221-229.

24. Bayliss EA, Ellis JL, Steiner JF. Barriers to self-management and quality-of-life outcomes in seniors with multimorbidities. *Ann Fam Med*. 2007;5(5):395-402.

25. Marengoni A, Rizzuto D, Wang H, Winblad B, Fratiglioni L. Patterns of chronic multimorbidity in the elderly population. *J Am Geriatr Soc*. 2009;57(2):225-230.

26. John R, Kerby DS, Hennessy CH. Patterns and impact of comorbidity and multimorbidity among community-resident American Indian elders. *Gerontologist*. 2003;43(5):649-660.

27. Cornell JE, Pugh JA, Williams Jr JW, et al. Multimorbidity clusters: Clustering binary data from multimorbidity clusters: Clustering binary data from a large administrative medical database. *Applied Multivariate Research*. 2009;12(3):163-182.

28. Schäfer I, von Leitner E, Schön G, et al. Multimorbidity patterns in the elderly: A new approach of disease clustering identifies complex interrelations between chronic conditions. *PloS one*. 2010;5(12):e15941.

29. Kirchberger I, Meisinger C, Heier M, et al. Patterns of multimorbidity in the aged population. results from the KORA-age study. *PloS one*. 2012;7(1):e30556.

30. Krein SL, Heisler M, Piette JD, Butchart A, Kerr EA. Overcoming the influence of chronic pain on older patients' difficulty with recommended self-management activities. *Gerontologist*. 2007;47(1):61-68.

31. Wolff JL, Boyd CM. A look at person-centered and family-centered care among older adults: Results from a national survey. *J Gen Intern Med*. 2015;30(10):1497-1504.

32. Kerr EA, Heisler M, Krein SL, et al. Beyond comorbidity counts: How do comorbidity type and severity influence diabetes patients' treatment priorities and self-management? *J Gen Intern Med*. 2007;22(12):1635-1640.

33. Kasper J, Freedman V. National health and aging trends study user guide: Rounds 1 & 2, final release. . 2014.

34. Sinclair AJ, Girling AJ, Bayer AJ. Cognitive dysfunction in older subjects with diabetes mellitus: Impact on diabetes self-management and use of care services. *Diabetes Res Clin Pract*. 2000;50(3):203-212.

35. Wolff JL, Spillman B. Older adults receiving assistance with physician visits and prescribed medications and their family caregivers: Prevalence, characteristics, and hours of care. *J Gerontol B Psychol Sci Soc Sci*. 2014;69 Suppl 1:S65-72.

36. Gutiérrez-Maldonado J, Caqueo-Urízar A. Effectiveness of a psycho-educational intervention for reducing burden in Latin American families of patients with schizophrenia. *Qual Life Res*. 2007;16(5):739-747.

37. Cahill E, Lewis LM, Barg FK, Bogner HR. "You don't want to burden them": Older adults' views on family involvement in care. *J Fam Nurs*. 2009;15(3):295-317.

38. Kasper JD, Freedman VA, Spillman B. Classification of persons by dementia status in the national health and aging trends study. technical paper #5. 2013.

39. Wallhagen MI, Strawbridge WJ, Shema SJ, Kurata J, Kaplan GA. Comparative impact of hearing and vision impairment on subsequent functioning. *J Am Geriatr Soc*. 2001;49(8):1086-1092.

40. Löwe B, Wahl I, Rose M, et al. A 4-item measure of depression and anxiety: Validation and standardization of the patient health questionnaire-4 (PHQ-4) in the general population. *J Affect Disord*. 2010;122(1):86-95.

41. Morris JC. Revised criteria for mild cognitive impairment may compromise the diagnosis of Alzheimer disease dementia. *Arch Neurol*. 2012;69(6):700-708.

42. Seshadri S, Beiser A, Au R, et al. Operationalizing diagnostic criteria for Alzheimer's disease and other age-related cognitive impairment—Part 2. *Alzheimers Dement*. 2011;7(1):35-52.

43. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged: The index of ADL: A standardized measure of biological and psychosocial function. *JAMA*. 1963;185(12):914-919.

44. Allen SM, Piette ER, Mor V. The adverse consequences of unmet need among older persons living in the community: Dual-eligible versus medicare-only beneficiaries. *J Gerontol B Psychol Sci Soc Sci*. 2014;69 Suppl 1:S51-8.

45. Freedman VA, Kasper JD, Cornman JC, et al. Validation of new measures of disability and functioning in the national health and aging trends study. *J Gerontol A Biol Sci Med Sci*. 2011;66(9):1013-1021.

46. Freedman VA, Spillman BC. Disability and care needs among older americans. *Milbank Q*. 2014;92(3):509-541.

47. May CR, Eton DT, Boehmer K, et al. Rethinking the patient: Using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res*. 2014;14(1):281.

48. Shippee ND, Shah ND, May CR, Mair FS, Montori VM. Cumulative complexity: A functional, patient-centered model of patient complexity can improve research and practice. *J Clin Epidemiol*. 2012;65(10):1041-1051.

49. Bernhard J, Maibach R, Thurlimann B, Sessa C, Aapro MS, Swiss Group for Clinical Cancer Research. Patients' estimation of overall treatment burden: Why not ask the obvious? *J Clin Oncol*. 2002;20(1):65-72.

50. Henry DH, Viswanathan HN, Elkin EP, Traina S, Wade S, Cella D. Symptoms and treatment burden associated with cancer treatment:

Results from a cross-sectional national survey in the US. *Support Care Cancer*. 2008;16(7):791-801.

51. Sav A, King MA, Whitty JA, et al. Burden of treatment for chronic illness: A concept analysis and review of the literature. *Health Expect*. 2015; 18(3):315-324.

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Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services

Best Masters Thesis Award
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Department of Health Policy and Management, University of Minnesota

Outstanding MS Poster Presentation Award
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Research Assistant to Dr. Mariana Lazo, Dr. Hsin-Chien Yeh, and Dr. Albert Wu
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Johns Hopkins University, Baltimore, MD

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Research Assistant to Dr. Hadi Kharrazi and Dr. Jonathan Weiner
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Johns Hopkins University, Baltimore, MD

- Developed research proposals, performed data analysis, and coordinated research activities for comparing performance of predictive models using claims data and electronic health records

Summer Research Fellow
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Agency for Healthcare Research and Quality, Rockville, MD

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Research Analyst Sr.
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HealthCore Inc., Wilmington, DE

- Conducted research to support decision making for payers and providers
- Leaded research projects including protocol development, results review & dissemination

Research Analyst
2010- 2011
HealthCore Inc., Wilmington, DE

- Conducted research to support WellPoint/Anthem Inc.'s decision making
- Contributed to protocol development and performed data analysis

Data Manager and Analyst to Mr. Dave Knutson & Dr. Bryan Dowd
2009-2010
University of Minnesota, Minneapolis, MN

- Cooperated with CMS, Alternative Approaches to Measuring Physician Resource Use Project Developed a measure and a risk-adjustment method to evaluate resource use of physicians
- Performed data analysis on the Medicare data using SQL & SAS® Version 9.1 software

Research Assistant to Dr. Karen Kuntz
2008-2010
University of Minnesota, Minneapolis, MN

- Collaborated with Cancer Intervention and Surveillance Modeling Network
- Evaluated cost-effectiveness of screening policies for colorectal cancer using TreeAge®

Research Assistant to Dr. John Nyman
2008-2009

- Contracted with State of Minnesota, Greater Twin Cities United Way Health Care Reform Model Project
- Conducted literature review on price and quality transparency

TEACHING EXPERIENCE

Teaching Assistant
Johns Hopkins University, Baltimore, MD

- Quality of Medical Care (two consecutive years)
  2013-2014
- Assessing Health Status and Patient Outcomes (two consecutive years)
  2013-2014
- Managed Care and Health Insurance (two consecutive years)
  2013-2014
- Health Services Research Doctoral Student Seminar
  2014-2015

SERVICE

Co-chair, Student Coordination Center for Department of Health Policy and Management
2013-2014
Volunteer, Green Hour Program–Fight Childhood Obesity, New Castle, DE
2011-2012
Instructor, (7th grade) at Ming-De Chinese School, Wayne, PA
2011-2012
Volunteer, Ebenezer - Fairview Health Services for Senior Living, Minneapolis, MN

2008
Volunteer, Vitas Innovative Hospice Care® , Eatontown, NJ
2007

PUBLICATIONS

Chi W, Sylwestrzak, G, Barron J, Kasravi B, Power T, Redberg R. Does CAC Testing Alter Downstream Treatment Patterns for Cardiovascular Disease? *American Journal of Managed Care.* 2014, 20(8):e330-9.

Chi W, Wu S-j, DeVries A. A Reference-Based Purchasing Design Increases Use of High-Value Facilities: Equivalent Quality at Lower Costs [Letter to the Editor]. *Health Affairs.* 2014 33:723.

Dowd B, **Li C-h**, Swenson T, Caplan C, Levy J. Early Results from the Medicare Physician Quality Reporting System (PQRS): Quality Measurement and Beneficiary Attribution. *Medicare and Medicaid Research Review*. 2014, 25(4);2.

DeVries A, Koch T, Wall E, Getchius T, **Li C-h**, Rosenberg A. Opioid Use Among Adolescent Patients Treated for Headache. *Journal of Adolescent Health*. 2014, 55(1): 128-133

DeVries A, **Li C-h**, Oza M. Strategies to Reduce Nonurgent Emergency Department Use: Experience of a Northern Virginia Employer Group. *Medical Care*, 2013, 51(3):224-30.

DeVries A, Getchius T, Wall E, Young P, **Li C-h**, Whitney J, Rosenberg A. CT Scan Utilization Patterns in Pediatric Patients with Recurrent Headache. *Pediatric*. 2013, 132(1):e1-8.

DeVries A, **Li C-h**, Sridhar G, Hummel JR, Breidbart S, Barron J. Comparing Quality, Healthcare Utilization and Costs for Patient-Centered Medical Home (PCMH) and non-PCMH Patients in the Pre-recognition Period. *American Journal of Managed Care*, 2012, 18(9):534-44.

Nyman JA, **Li C-h**. Price and quality transparency. *Minnesota Medicine*, July 2009.

CONFERENCE PRESENTATIONS

Podium

DeVries A, **Chi W**, Uscher-Pines L, Mehrotra A. "One-Stop Shopping: Characteristics and Preferences of Insured Individuals Treated at Retail Health Clinics." ***Oral podium presentation*** at Annual Research Meeting of AcademyHealth, San Diego, CA, USA. June, 2014.

Li C-h, Wu S-j, Belman M, DeVries A. "Effects of a Reference-Based Purchasing Design Program on Healthcare Utilization and Outcomes of Knee and Hip

Replacement Surgeries".
Oral podium presentation at Annual Research Meeting of AcademyHealth, Baltimore, MD, USA. June, 2013.

Li C-h, Oza M, DeVries A. "Strategies to Reduce Non-Emergent ER Use: Experience of an Employer Group in Northern VA".
Oral podium presentation at Annual Research Meeting of AcademyHealth, Seattle, WA, USA. June, 2011

Poster

DeVries A, **Chi W**, Uscher-Pines L, Mehrotra A. "Characteristics of Rational Emergency-departments Users".
Poster presentation at Annual Research Meeting of AcademyHealth, San Diego, CA, USA. June, 2014.

Barron J, **Li C-h**, Sylwestrzak G, Kasravi B, Power T, Redberg R. "Impact of Coronary Artery Calcium Testing on Downstream Imaging, Interventions and Adverse Ischemic Events".
Poster presentation at American College of Cardiology Conference 13, San Francisco, CA, USA. March, 2013.

Li C-h, Agiro A, Talnose D, Oza M, DeVries A. "Can Educational Outreach Alone Reduce Non-emergent ER Use? Lessons from Employer Groups in Connecticut".
Poster presentation at Annual Research Meeting of AcademyHealth, Orlando, FL, USA. June, 2012.

DeVries A, **Li C-h**, Sridhar G, Hummel JR, Breidbart S, Barron J. "Comparing Quality, Healthcare Utilization and Costs for Patient-Centered Medical Home (PCMH) and non-PCMH Patients in the Pre-recognition Period".
Poster presentation at Annual Research Meeting of AcademyHealth, Seattle, WA, USA. June, 2011.

Li C-h, Kuntz K. "Cost-Effectiveness Analysis for Various Colorectal Cancer Screening Strategies in Taiwan".
Poster presentation at Annual Meeting of Society for Medical Decision Making, Toronto, ON, Canada. October, 2010.